


Fall 2010

# Athlete and Coach Knowledge, Attitudes, and Perceptions of Sickle Cell Trait and National Collegiate Athletic Association Mandated Testing: Recommendations for Intervention

Raymona Holloway Lawrence  
*Georgia Southern University*

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ATHLETE AND COACH KNOWLEDGE, ATTITUDES, AND PERCEPTIONS OF SICKLE CELL TRAIT AND  
NATIONAL COLLEGIATE ATHLETIC ASSOCIATION MANDATED TESTING:

RECOMMENDATIONS FOR INTERVENTION

by

RAYMONA HOLLOWAY LAWRENCE

(Under the Direction of Mondri Mason)

ABSTRACT

Individuals with Sickle Cell Trait have died suddenly after extreme exertion during military training, athletic practice or games (Kerle & Nishimura, 1996; Harrelson, Fincher & Robinson, 1995; Howe & Bowden, 2007). One of those deaths, Dale Lloyd, a football player at Rice University, prompted a change in the National Collegiate Athletic Association's (NCAA) Sports Medicine Handbook Guideline 3c: *The Student Athlete with Sickle Cell Trait*. Effective August 2010, the NCAA Division I Proposal No. 2009-75-B mandated sickle cell trait testing in all Division I athletes unless documented results of a prior test are provided to the institution or the student-athlete declines the test and signs a written release.

It is well-documented that in the United States, Sickle Cell Disease/Sickle Cell Trait primarily affects African Americans more than any other race or ethnicity (NIH, 2008). Sickle cell screening programs have been scrutinized since the 1970s (Pemberton & Wailoo, 2006) because of insensitivity to race. The recent change in NCAA Guideline 3c has been scrutinized partially for the same reason.

The purpose of this mixed methods study was threefold. It was necessary to 1) determine perceptions of SCT and NCAA mandated SCT testing from college coaches and

athletes' points of view; 2) determine the necessary components of the Sickle Cell Orientation and Education (S.C.OR.E) intervention that will be developed to educate intercollegiate athletes, as well as their coaches, about sickle cell trait from pre-participation screening to sickle cell trait diagnosis, and 3) to highlight the potential implications of an NCAA policy that mandates SCT testing.

The PRECEDE-PROCEED (PRE-PRO) model of program planning was utilized to determine the necessary components of the intervention (Green & Kreuter, 1999). Constructs of the Health Belief Model (HBM) and Critical Race Theory (CRT) were utilized as the theoretical framework for this study. It was found that knowledge, perceived importance of an athlete knowing his/her SCT status, perception of NCAA 3c resulting in unfair treatment of athletes, perception of receiving less playing time, and perception of risk of having SCT were all associated with athletes' outlooks on SCT and NCAA SCT testing. Overall, athletes and coaches did not perceive that athletes with SCT would be discriminated against. Individual, organizational, and policy recommendations were made to address this issue.

**INDEX WORDS:** Sickle cell anemia, Sickle cell trait, Exercise, College, Athlete, Racism, NCAA, NCAA Guideline 3c, Policy, Exertional rhabdomyolysis

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RAYMONA HOLLOWAY LAWRENCE

B.S. Georgia Southern University, 2000

M.P.H. Georgia Southern University, 2003

A Dissertation Submitted to the Graduate Faculty of Georgia Southern University in

Partial Fulfillment of the Requirements for the Degree

DOCTOR OF PUBLIC HEALTH

STATESBORO, GEORGIA

2010

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RAYMONA HOLLOWAY LAWRENCE

Major Professor:  
Committee:

Mondi Mason  
Cassandra Arroyo  
Alison Scott

Handwritten signatures of Mondy A. Mason, Cassandra Arroyo, and Alison Scott.

Electronic Version Approved:  
December 2010

## DEDICATION

I would like to dedicate this dissertation to all those who have sickle cell disease and who have ever been discriminated against because of it. I would also like to dedicate it to the athletes who have been or will be diagnosed with sickle cell trait. I pray that this work will in some way protect you from any negativity that might surround a sickle cell trait diagnosis. Continue to play hard and be all that you can be! Know that I will always fight for you. May God bless all who are in any way connected with sickle cell disease. I literally feel your pain...

## ACKNOWLEDGEMENTS

I would like to acknowledge the following people for their support throughout this process:

My Lord and Savior Jesus Christ without whom I could and would be nothing and with whom all things are possible.

My committee members: Drs Mondi Mason, Cassandra Arroyo, and Allison Scott. Your expertise and guidance was greatly appreciated throughout this process. Thank you for sticking by me! Dr. Mason, you have taught me most of what I know about public health practice and I will always call you my mentor, my teacher...my friend.

My family: Mom and Dad, thank you for your love and support. I would not have gotten through this process without the life lessons you taught me, the encouragement, and all the entertainment you gave Ge Ge! George and my little Ge Ge: Thank you for your understanding as I have gone through this process. George your love has been unparalleled and there is no way I could have done this with our small child if you weren't so supportive. I am forever grateful! Ge Ge, I started this process when you were four months old. You have only known me as a student/mommy, but I find comfort in knowing that you will never remember the student days and from now on, you will only know me as "mommy"!!

My friends: Sarah (Dr. P!), Krista, Nandi, Kelley (Dr. C!), Kendria, Patrice, my CRI till you die coworkers, and the rest of the 1<sup>st</sup> and 2<sup>nd</sup> cohorts of the Jiann Ping Hsu College of Public Health. Thanks for your encouraging words and prayers!



Drs. Hardy and Woodhouse. Thank you for your leadership in developing the Jiann Ping Hsu College of Public Health. Your passion for public health is contagious; and I will carry this same passion with me as I practice public health in the future.

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## CHAPTER 1

### INTRODUCTION

#### Introduction

The death of Dale Lloyd, an athlete at Rice University, in 2006 brought about major revisions to National Collegiate Athletic Association (NCAA) sickle cell trait (SCT) screening policy. Lloyd collapsed at football practice and died the next day. His death was attributed to acute exertional rhabdomyolysis (rapid breakdown of muscle tissue due to extreme exertion) associated with sickle cell trait. Lloyd's family sued the NCAA and Rice University. As a result, the NCAA recommended and subsequently developed a policy that mandated SCT testing for all athletes during the pre-participation medical examination (NCAA, 2010).

#### *Sickle Cell Disease*

The focus of this study is sickle cell trait. However, in order to understand sickle cell trait, it is necessary to become familiar with sickle cell disease. Sickle cell disease (SCD) is a genetic disorder caused by the mutation of hemoglobin (Hb) A into hemoglobin S. Hemoglobin is the oxygen carrying component of the blood. The mutation of hemoglobin causes cells to develop an "S" or sickle shape, which gives the condition its name.

In the United States, there are over 2,000 babies born with sickle cell disease each year. Approximately 80,000 Americans have the disease with more carrying the genetic trait, which can be passed on to children. The disease occurs in about one in every 500 African-American births, 1 in every 36,000 Hispanic-American births, and 1 in every 100,000 Caucasian births (National Institutes of Health, 2008).

Sickle cell disease is a major public health concern, as it can dramatically affect the health and quality of life of those diagnosed with the disease. When someone has SCD, they can experience a sickle cell “crisis”. This crisis occurs when pain, often with a sudden onset, occurs because of decreased blood flow to tissues of the body. The sickle-shaped cells essentially “get stuck” in blood vessels, causing occlusions and tissue damage (Centers for Disease Control, 2008). People with sickle cell disease have a shortened life expectancy. Platt et al. (1994) followed 3764 patients who ranged from birth to 66 years of age at enrollment to determine the life expectancy and calculate the median age at death. It was found that among children and adults with sickle cell anemia (homozygous for sickle hemoglobin), the median age at death was 42 years for males and 48 years for females.

#### *Sickle Cell Trait*

Having sickle cell disease is clinically different than having sickle cell trait. Although sickle cell disease is noted as a major public health problem, sickle cell trait (SCT) is generally regarded as a benign condition. About 2 million Americans or 1 in 12 African Americans carry the SCT (National Institutes of Health, 2008). People with SCT, also known as hemoglobin AS, have no related anemia or joint pains that people with SCD have, and typically have a normal life expectancy.

There is limited, scientific research on the associations of SCT status with compromised health (Treadwell, 2006). Studies have been published that confirm the association between SCT and extreme exertion (Kerle & Nishimura, 1996; Harrelson, Fincher & Robinson, 1995; Howe & Bowden, 2007). However, controversy continues to surround sickle cell trait and its association with exercise related morbidity and sudden death (Mitchell, 2007).

Individuals with SCT have died suddenly after extreme exertion during military training, athletic practice or games (Kerle & Nishimura, 1996; Harrelson, Fincher & Robinson, 1995; Howe & Bowden, 2007). One of those deaths (Dale Lloyd noted above) prompted a change in the National Collegiate Athletic Association's (NCAA) Sports Medicine Handbook Guideline 3c: *The Student Athlete with Sickle Cell Trait*. The guideline recommends SCT screening for all athletes and states, "If screening is done, it may be done on a voluntary basis with the informed consent of the student-athlete and should be offered to all student-athletes, because sickle cell trait occurs in all populations" (NCAA, 2010). Effective August 2010, the NCAA Division I Proposal No. 2009-75-B mandated sickle cell trait testing in all Division I athletes unless documented results of a prior test are provided to the institution or the student-athlete declines the test and signs a written release. This is different from the earlier recommendation in that if athletes opt out of testing, they have to release the NCAA of liability if injury were to occur that was attributed to SCT.

#### *The Problem with Mandatory Screening*

The NCAA has mandated SCT screening for all college athletes. However, it is well-documented that in the United States, SCD/SCT primarily affects African Americans more than any other race or ethnicity (NIH, 2008). Sickle cell screening programs have been scrutinized since the 1970s (Pemberton & Wailoo, 2006) because of lack of sensitivity to race. Programs have been developed without examination of the social implications that screening may have on an entire ethnic group if a disease is predominate in a particular race. The recent change in NCAA Guideline 3c has been scrutinized partially for the same reason. Legislation is often passed by individuals who may be unaware of the history of mass genetics screening. This lack

of knowledge has implications for discrimination towards SCT carriers in the present and in the future. Hematologists, other medical professionals, and those who advocate for people with sickle cell disease or trait (hereafter referred to as 'the sickle cell community'), are concerned that there may not be enough evidence of the association of sickle cell trait to sudden death in athletes to warrant this type of policy. Concerns about the policy leading to discrimination towards sickle cell trait carriers within college athletics are also at the forefront of this debate. The NCAA developed the policy to mandate SCT screening among all Division I athletes. However, policy is not in place that mandates protection from possible negative implications for those who are diagnosed with SCT. Therefore, it is necessary to examine sickle cell screening among intercollegiate athletes thoroughly and critically so that social justice issues (e.g., discriminatory practices based on race) will not surface as an unintended consequence of mass screening.

#### *Sickle Cell Legislation and Unintended Consequences*

In the 1970s, legislation was passed that mandated screening for SCD/SCT. The Sickle Cell Disease Control Act of 1972 (PL-92-294) increased federal support for SCD treatment and research and initiated SCD education and screening programs in the United States. The legislation increased the knowledge and awareness of SCD among African Americans as well as other ethnicities. However, it also provoked many new controversies among African Americans such as fears of racism and being perceived as genetically inferior (Hill, 1994; Wailoo, 2001).

The SCT gene primarily affects those who are of African descent. Therefore, African Americans (AA) were racially targeted by screening programs. Researchers have suggested that the early sickle cell screening programs may have been criticized because of the perceived

racism surrounding the disease (Wailoo, 2001). Atkin and Ahmad (1998) stated that public recognition of sickle cell disorders in the United States was accompanied by the suggestion that the existence of SCD among African Americans proved genetic inferiority. Further, criticisms of early sickle cell screening programs included controversy surrounding the accuracy and validity of the early screening tests; and inadequate protection of the patients' rights (Markel, 1992).

#### Statement of the Problem

NCAA Division I Proposal No. 2009-75-B (mandatory sickle cell testing for all athletes) faces many of the same criticisms as previous mandatory screening programs. The sickle cell community has voiced concerns about universal SCT testing (Allday, 2009) over concern about its social and behavioral implications such as discrimination against athletes with sickle cell trait. A sickle cell expert and director of hematology and oncology at Children's Hospital Oakland stated, "A coach is going to be able to say, 'Even though this kid is great, do I really want to put him out there as a quarterback or starting player and take the risk of something happening?'" (Allday, 2009). The controversy stems from the fact that there is little evidence to legitimate the assumption that SCT causes sudden death. Though deaths have been documented, more scientific evidence is needed to substantiate the link between SCT and sudden death. Also, it is believed that since sickle cell trait primarily affects African Americans, this policy will do more harm than good to African American players because they may be discriminated against by college athletic programs because of possession of the sickle cell trait.

The implications of sickle cell trait screening policy should be closely examined. Education of all involved, including coaches, athletic trainers, and athletes, will likely dispel fears and reduce the likelihood that discrimination among athletes with the sickle cell trait will

occur. There is a need for a standardized sickle cell trait education program that the NCAA can disseminate among its member colleges and universities. The standardized program is necessary to educate coaches, athletic trainers, and players about sickle cell trait from pre-participation screening to possible diagnosis with SCT. More importantly, there is also a need for the NCAA to develop policy that will ensure the protection of athletes who are diagnosed with SCT.

### Purpose of the Study

The purpose of this study was threefold. It was necessary to 1) determine perceptions of SCT and NCAA mandated SCT testing from college coaches and athletes' points of view; 2) determine the necessary components of the Sickle Cell Orientation and Education (S.C.O.R.E) intervention that will be developed to educate intercollegiate athletes, as well as their coaches, about sickle cell trait from pre-participation screening to sickle cell trait diagnosis, and 3) to highlight the potential implications of an NCAA policy that mandates SCT testing. Because of the recent NCAA legislation, there has not yet been a standardized program developed to educate coaches and athletes about sickle cell trait. The NCAA recently developed an educational video as well as handouts for athletes and coaches concerning SCT. However, there is still not a standardized process outlined for member colleges and universities to utilize from pre-participation screening to possible SCT diagnosis. There are also no policies dedicated to the protection of athletes who are diagnosed with SCT. NCAA mandated testing is not beneficial if "once tested, [athletes] are not made aware of their results and counseled as to the implication of the result and processes are not put in place to ensure that the result is accessible to relevant health professionals who may need to offer the individual future

healthcare (Davies & Oni, 2001, pg. 301)". Therefore, a goal of this study was to offer recommendations for an effective intervention.

#### *Program Planning Approach to the Study*

The PRECEDE-PROCEED (PRE-PRO) model of program planning was utilized to determine the necessary components of the intervention (Green & Kreuter, 1999). The PRE-PRO model of program planning is the most widely known model of program planning. It is respected professionally because it is theoretically grounded and comprehensive. The complete model includes eight phases. The first four phases consist of a series of planned assessments that are used to guide programming decisions (McKenzie, Neiger, and Thackeray, 2009). The eight phases of PRE-PRO are as follows: 1) Social Assessment/Situational Analysis, 2) Epidemiological Assessment, 3) Educational and Ecological Assessment, 4) Administrative and Policy Assessment and Intervention Alignment, 5) Implementation 6) Process Evaluation 7) Impact Evaluation, and 8) Outcome Evaluation. Figure 1 illustrates the PRECEDE-PROCEED model of program planning (Green & Kreuter, 2005).



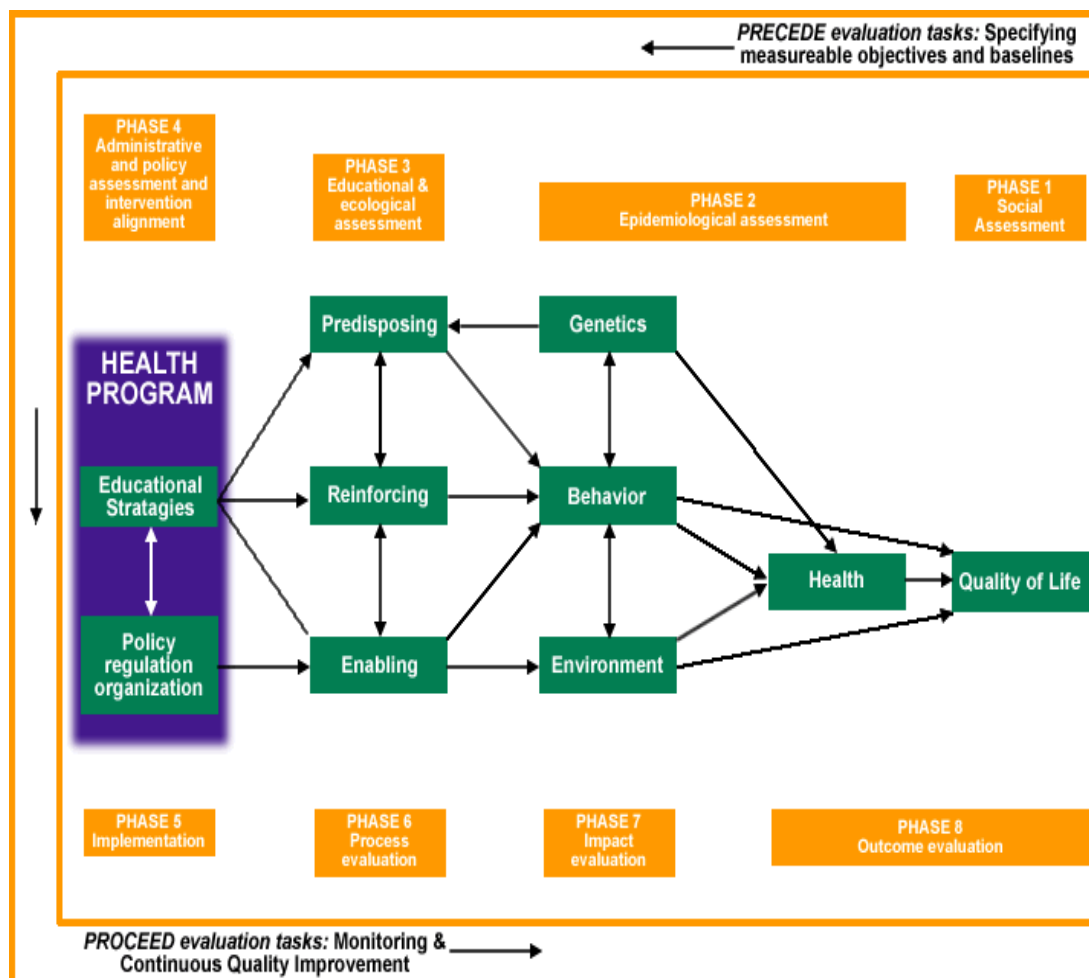


Figure 1. Generic Representation of the Precede-Proceed Model. From L. Green and M. Kreuter. (2005). *Health Promotion Planning: An Educational and Ecological Approach* (4<sup>th</sup> Ed.). Mountain View, CA : Mayfield Publishers  
[http://ctb.ku.edu/en/tablecontents/sub\\_section\\_main\\_1008.aspx](http://ctb.ku.edu/en/tablecontents/sub_section_main_1008.aspx)

The first four phases: 1) Social Assessment/Situational Analysis, 2) Epidemiological Assessment, 3) Educational and Ecological Assessment, and 4) Administrative and Policy Assessment and Intervention Alignment were utilized in this formative study to determine the necessary components of an intervention that will be developed to educate intercollegiate athletes, as well as their coaches, about sickle cell trait from pre-participation screening to sickle cell trait diagnosis.

## Research Questions

The research questions for the current study were aligned with the first four phases of the PRECEDE-PROCEED model of program planning and are as follows:

### Overarching Research Question

What are the necessary components of the Sickle Cell Orientation and Education (S.C.OR.E.) intervention that will be developed to educate intercollegiate athletes, as well as their coaches, about sickle cell trait from pre-participation screening to sickle cell trait diagnosis? The answer to this question was determined by answering a series of sub-questions that were aligned with the first four phases of the PRE-PRO model of program planning. The educational/ecological assessment is the primary assessment within the study. It was determined during the research design phase that this assessment would yield the most pertinent information to design an education program. This assessment examined the participants' knowledge, attitudes, and perceptions of SCT and NCAA mandated SCT testing. The remaining phases were utilized as secondary assessments because the information they yielded supported contextual necessities of the educational/ecological assessment. Table 1 illustrates the educational and ecological research questions and their associated hypotheses. Table 2 illustrates the research questions that were associated with the social assessment and situational analysis, epidemiological assessment, and intervention alignment and administration and policy assessment.

Table 1  
*Research Questions: Educational and Ecological Assessment*

Research Questions	Hypotheses
What are the predisposing, enabling, and reinforcing factors that influence coaches and athletes' outlook on SCT testing?	Hypothesis 1: Knowledge of SCT is not associated with athlete outlook on SCT testing
	Hypothesis 2: Perceived risk of having SCT is not associated with athlete outlook on SCT testing
	Hypothesis 3 : Perceived importance of knowing he/she has SCT is not associated with athlete outlook on SCT testing
What are the predisposing, enabling, and reinforcing factors that influence coaches and athletes' outlook on NCAA guideline 3c?	Hypothesis 4: Knowledge of NCAA 3c is not associated with athlete outlook on NCAA 3c.
	Hypothesis 5: Perception that NCAA 3c might result in athletes with SCT being treated unfairly is not associated with athletes' outlooks on NCAA 3c
	Hypothesis 6: Athletes' perceptions of receiving less playing time if he/she was diagnosed with SCT is not associated with outlook on NCAA 3c
Do the predisposing, enabling, and reinforcing factors that influence coaches and athletes' outlooks on SCT and NCAA guideline 3c differ among ethnic groups?	Hypothesis 7: Knowledge of SCT will not differ among ethnic groups
	Hypothesis 8: Perceived risk of having SCT will not differ among ethnic groups
	Hypothesis 9 : Perceived importance of knowing he/she has SCT will not differ among ethnic groups
	Hypothesis 10: Knowledge of NCAA 3c will not differ among ethnic groups
	Hypothesis 11: Perception that NCAA 3c might result in athletes with SCT being treated unfairly will not differ among ethnic groups
Hypothesis 12: Athletes' perceptions of receiving less playing time if he/she was diagnosed with SCT will not differ among ethnic groups	

Table 2

*Research Questions: Social Assessment and Situational Analysis, Epidemiological Assessment, and Intervention Alignment and Administrative and Policy Assessment*

---

**Social Assessment and Situational Analysis.**

What happens during a pre-participation physical?

How are athletes educated about health information discovered in pre-participation physicals?

How do athletes want to be educated about information received on pre-participation physicals?

What concerns do athletes have about health issues being revealed in pre-participation physicals?

**Epidemiological Assessment**

What are the genetic, behavioral and environmental factors that are associated with sickle cell trait and the intercollegiate athlete?

**Intervention Alignment and Administrative and Policy Assessment**

What capabilities and resources are necessary to develop an intervention that will educate intercollegiate athletes, as well as their coaches, about sickle cell trait from pre-participation screening to sickle cell trait diagnosis?

---

**Theoretical Framework**

Constructs of the Health Belief Model (HBM) and Critical Race Theory (CRT) were utilized as the theoretical framework for this study. Each of these theories is explained below.

*Health Belief Model*

The HBM is a value expectancy theory meaning that the desire to avoid illness (value) interacts with the belief that a health action, like SCT screening, would prevent illness (expectancy) (Strecher & Rosenstock, 1996). Perception is an integral part of this theory. In this study, constructs of the HBM were utilized to determine athletes' perceptions about susceptibility, benefits, and barriers of SCD/SCT. This information was then utilized to determine if differences among ethnicities affected the college athletes' perceptions of sickle cell trait and NCAA recommendation 3c (and mandatory SCT screening).

*Critical Race Theory*

Critical Race Theory (CRT) is a conceptual lens used to examine racism, racial (dis)advantages, and inequitable distribution of power and privilege within institutions and

society (Bell, 1987; Delgado & Stefancic, 2001). CRT challenges the notions of colorblindness, merit, and racial equity, and also tests the innocence of self-proclaimed white liberals and sparks awareness that leads to social justice and the advancement of people of color (Crenshaw, Gotanda, Peller, & Thomas, 1995).

The study utilized CRT as a lens to examine the policy implications of NCAA Guideline 3c. Although NCAA Guideline 3c was only a recommendation at the initiation of this study, many schools were still choosing to test athletes for SCT (Clarke, 2006). Therefore, it was important to critically analyze the implications that this NCAA policy mandate may have had on African American athletes as a result of “race” or ethnicity.

#### Significance of the Study

The significance of the study is that it is timely. Since the NCAA mandate recently occurred in 2010, no other published study has examined college athletes’ perspectives of the mandate and SCT screening. Also, no other study has examined the knowledge and perceptions of both African Americans and Caucasians concerning SCT. No other study has utilized a CRT perspective in the examination of the issue. There are no published studies that compare differences in perceptions of SCT screening among individuals who are highly susceptible (i.e. African Americans) versus those who are minimally susceptible (i.e. Caucasians) to the SCT. There are also no education programs that are tailored to the needs of intercollegiate athletes who possess the sickle cell trait, as well as their coaches. This study also highlights the possible implications of mandatory SCT testing and offers recommendations to avoid negative consequences (i.e. discrimination) for the athlete with SCT. The use of the

Health Belief Model as well as Critical Race Theory served to intertwine the athletes' perceptions with often unseen issues of institutional racism and social injustice.

#### Delimitations

Male and female athletes who played on one of the 13 NCAA governed intercollegiate sports teams at Georgia Southern University in the summer of 2010 were included in this study. Georgia Southern University is a predominately white (~70%) regional university in South Georgia. There are approximately 20,000 students who attend the university. The size and location of the university have implications for the study. The views expressed within this study are those of athletes and coaches who attend school, live, and work in a small, southern town. The views of those in a different region of the country or in smaller or larger schools may vary.

#### Chapter Summary/Organization of the Dissertation

The National Collegiate Athletic Association (NCAA) recently developed policy that required all of its member colleges and universities to test every athlete for SCT. Sickle cell trait screening has been met with controversy since the 1970s. Therefore, it is imperative that sickle cell trait screening programs be examined thoroughly for educational worthiness and to ensure that discrimination against athletes of color does not occur as a result of mass screening.

One purpose of this study was to determine the necessary components of the intervention that will be developed to educate intercollegiate athletes, as well as their coaches, about sickle cell trait from pre-participation screening to sickle cell trait diagnosis. The PRECEDE-PROCEDE Model of program planning was utilized as a guide for program planning. The Health Belief Model and Critical Race Theory served as the theoretical basis for the study.

Chapter 2 outlines the literature concerning sickle cell trait and the athlete. A review of topics such as sickle cell disease/trait, racism, sickle cell policy, NCAA guideline 3c, and sickle cell trait and sudden death will be included in this discussion.

Chapter 3 will describe the research methodology that was utilized in the study. The chapter describes the purpose of the study. Quantitative and qualitative research design, research questions, sampling methodology, data collection and data analysis techniques are also described explicitly in chapter three.

Chapters 4 and 5 will describe the quantitative and qualitative findings of the study respectively. The findings are outlined based upon the PRECEDE-PROCEED model of program planning. Quantitative and qualitative data are integrated in the educational/ecological assessment. The findings from the remaining assessments are based upon qualitative inquiry.

Chapter 6 provides a discussion of the findings as well as conclusions, implications for policy and practice, and recommendations for future research. These findings are outlined based upon three stages of the PRECEDE-PROCEED model of program planning which provided, in part, the theoretical foundation of this study. The discussion of findings begins with individual level factors. Next, organizational and policy factors will be discussed to broaden the scope of the recommendations for intervention. Finally, information that emerged during the intervention alignment phase will offer information concerning contextual factors that will affect the effectiveness of the intervention.

Following the findings from the PRECEDE-PROCEED assessment will be a discussion of the necessary components of an intervention designed to educate coaches and athletes about

SCT. The final sections of the chapter will include a conclusion, recommendations for policy and practice, recommendations for future research, and limitations of the study.



## CHAPTER 2

### LITERATURE REVIEW

#### Introduction

This chapter begins with a discussion of sickle cell disease and trait. It will then outline a review of literature that will describe the problem addressed in this study. The chapter will explain how the National Collegiate Athletic Association (NCAA) came to the decision to test all athletes for sickle cell trait. It will also describe the controversy surrounding this decision. The theoretical framework that serves as a foundation for the study will be explained. Finally, the need for an education program will be described.

#### *Sickle Cell Disease*

The World Health Organization has called sickle cell disease a critical public health issue. Sickle cell anemia affects millions throughout the world. It is particularly common among people whose ancestors come from sub-Saharan Africa; Spanish-speaking regions (South America, Cuba, Central America); Saudi Arabia; India; and Mediterranean countries such as Turkey, Greece, and Italy. Throughout the world, sickle cell trait is seen in one in four West Africans; one in 10 African-Caribbeans; one in 50 Asians; one in 100 Greeks and occasionally in Northern Europeans (National Institutes of Health, 2008).

In the United States, there are over 2,000 babies born with sickle cell disease each year. Approximately 80,000 Americans have the disease with more carrying the genetic trait, which can be passed on to children. The disease occurs in about one in every 500 African-American births, 1 in every 36,000 Hispanic-American births, and 1 in every 100,000 Caucasian births. About 2 million Americans or 1 in 12 African Americans carry the sickle cell trait (National

Institutes of Health, 2008). From an evolutionary standpoint, carrying one sickle cell gene fended off death from malaria, leaving one in 12 African Americans versus one in 2,000 to one in 10,000 white Americans with sickle cell trait (National Athletic Trainer's Association, 2007).

Sickle cell disease (SCD) is caused by the mutation of hemoglobin (Hb) A into HbS. The mutation is caused by the substitution of a single amino acid, valine for glutamic acid (Monchanin et. al, 2006). The term sickle cell disease is used to describe a group of genetic disorders characterized by an abnormal hemoglobin labeled "S" (Jakubik, 2000). In the United States, of all the hemoglobinopathies, individuals with homozygous sickle cell genes (Hgb SS) have the greatest morbidity and mortality, and the disease limits their ability to participate in athletic activities. Hemoglobin carries oxygen in the blood. In sickle cell, this component of the blood is compromised. This compromise causes the cells to sickle or become crescent-shaped. The sickle-shaped cells can get stuck in blood vessels, causing occlusions, tissue damage, and pain (Centers for Disease Control, 2008). A sickle cell crisis occurs when pain, that is often sudden, is caused by decreased blood flow to tissues of the body (Centers for Disease Control, 2008). These episodes are unpredictable, often intense, and present a unique stressor for patients and their families (Jakubik, 2000).

Adverse effects of sickle cell include acute chest syndrome, severe anemia, cardiovascular instability, and bacterial sepsis. The lifespan of a healthy red blood cell is about 120 days, but that of a sickle cell is only about 20. This accounts for the anemia in sickle cell patients (Jakubik, 2000). Organ damage is also common among sickle cell patients. Many often have to undergo gall bladder and spleen removals. Another common occurrence in sickle cell

disease is deterioration of the hip and shoulder joints. This is known by the medical community as avascular necrosis (CDC, 2008).

The symptoms of this disease can be treated by a physician and most often at home by the patient him/her self. Hydration, over-the-counter pain relievers, and rest typically initiate treatment. If pain cannot be handled at home, patients are taken to the emergency department where they receive medical attention. They are often given a dose of morphine through an I.V. or administered non-steroidal anti-inflammatory drugs. Some patients also go through routine transfusions to replace some of the sickle shaped red blood cells (Mayo Clinic, 2007). The drug Hydroxyurea is used by many sickle cell patients to increase fetal hemoglobin and has also been proven to half the need for transfusion and the number of episodes of acute chest syndrome (CDC, 2008).

#### *Consequences of Having Sickle Cell Disease*

Because of the many visits to the doctor and emergency department that sickle cell warrants, patients with the disease are often stigmatized. They are often mistrusted by physicians and known as drug seekers. Patients are frequently not believed and are told that they are over or under exaggerating the pain they are in (Maxwell, Streetly, & Bevan, 1999). There is a mounting awareness that psychological and social factors may play significant and complex roles in the onset and maintenance of the most disabling feature of the disorder, the painful sickling crisis (Midence & Elander, 1996). The recurrent hospitalizations and severe physical complications can have catastrophic psychological and social consequences for people with sickle cell disease. Early disruption of education leads to poor qualifications, unemployment, and serious financial difficulties or poverty in adulthood (Midence & Elander,

1996). Children born to two parents with SCT have a 25% chance of having SCD and a 50% chance of having SCT (Treadwell, 2006).

### *Sickle Cell Trait*

Sickle cell trait is clinically different than sickle cell disease and is generally regarded as a benign condition. About 2 million Americans or 1 in 12 African Americans carry the sickle cell trait (SCT) (National Institutes of Health, 2008). People with SCT, also known as hemoglobin AS, have no related anemia or joint pains that people with SCD have and typically have a normal life expectancy.

There is limited, scientific research on the associations of SCT status with compromised health (Treadwell, 2006). Studies have been published that confirm the association between SCT and extreme exertion (Kerle & Nishimura, 1996; Harrelson, Fincher & Robinson, 1995; Howe & Bowden, 2007). However, a great deal of controversy continues to surround sickle cell trait and its association with exercise related morbidity and sudden death (Mitchell, 2007).

Individuals with SCT have died suddenly after extreme exertion during military training, athletic practice or games (Kerle & Nishimura, 1996; Harrelson, Fincher & Robinson, 1995; Howe & Bowden, 2007). The first known sickling death in college football was in 1974 when a defensive back ran a conditioning test on the first day of practice at altitude in Colorado. He had collapsed on the first day of practice the year before. This time, near the end of the first long sprint, at about 700 meters, he collapsed again-and died the next day. One of the most recent sickling deaths, Dale Lloyd, a freshman defensive back, at Rice University in the fall of 2006, was comparable. He collapsed after running 16 sprints of 100 yards each-and died the

next morning. The cause of death for both athletes was determined to be acute exertional rhabdomyolysis associated with sickle cell trait (NATA, 2007).

The death of Dale Lloyd prompted a lawsuit against the NCAA and Rice University. In reaction to the lawsuit, the NCAA recommended that all athletes be tested for sickle cell trait. In April 2010, the NCAA adopted legislation (NCAA Division I proposal 2009-75-B) that mandated sickle cell trait testing for all athletes. NCAA Sports Medicine Handbook guideline 3c: *The Student-Athlete with Sickle Cell Trait* was added to the handbook in 1975. Since that time, significant changes have been made to the guideline. The following section highlights the evolution of NCAA Sports Medicine Handbook Guideline 3c: *The Student-Athlete with Sickle Cell Trait*.

#### *Sickle Cell Trait and the College Athlete*

National Collegiate Athletic Association (NCAA) Sports Medicine Handbook Guideline 3c: *The Student-Athlete with Sickle Cell Trait* was added to the handbook in 1975. Since that time, with updates in medical knowledge concerning sickle cell trait, there have been multiple changes to the guideline with the latest change occurring in June 2008. In April 2010, NCAA Division I proposal 2009-75-B was adopted and therefore mandated SCT testing. The following is a detailed explanation of the changes in the guideline as well as an explanation of the recent SCT policy adopted by the NCAA.

In 1998, guideline 3c stated that “routine screening for sickle cell trait is not recommended”. The guideline listed an additional 4 points to be considered by athletics healthcare providers. 1) Team physicians and athletic trainers should familiarize themselves with medical literature concerning sickle cell, 2) no unwarranted restrictions should be placed

on the athlete with sickle cell trait, 3) If screening is done, it should be voluntary and offered to all athletes with athletes who test positive receiving genetics counseling for family planning, and explanation of risk involved with physical exertion. The final point was that all student athletes, including those with known SCT be counseled to a) avoid dehydration and acclimatize gradually to heat and humidity, b) condition carefully and gradually, c) acclimate to altitude over an appropriate amount of time, and d) refrain from extreme exercise during acute illness, especially one involving fever (NCAA, 1998).

In 2001, the wording in guideline 3c was verbatim to that of the 1998 revision with one exception. The first point to consider by health-care providers, “routine screening for sickle cell trait is not recommended” was removed. The 2008 revision of guideline 3c was much more direct in its wording. Sentences that, in 1998 and 2001, read, “sickle cell trait is not in itself a disease”, and “sickle cell trait condition (AS) is not the same as sickle cell anemia disease (SS)” were reworded to say “sickle cell trait is not a disease”, and “sickle cell trait (AS) is not sickle cell anemia (SS)” respectively. Examples of sickle-related death in the armed forces as well as athletics were added to the latest revision (2008). The guideline states that screening as part of the medical examination (sports physical exam) process is an institutional decision, but is recommended because although children are tested at birth, often families are unaware of a positive SCT result.

Precautions for the student-athlete with sickle cell were also outlined in the 2008 revision, whereas they were suggested for all athletes in earlier versions. The NCAA recommends that the student athlete with SCT should 1) set their own pace, 2) engage in slow and gradual preseason conditioning, 3) build up slowly while training, 4) use adequate rest and

recovery between repetitions, 5) not be urged to perform all out exertion beyond 2-3 minutes, 6) be excused from performance tests if it is not a normal sport activity, 7) stop activity immediately upon struggling or experiencing symptoms such as muscle pain or abnormal weakness, 8) stay well hydrated at all times, 9) maintain proper asthma management, 10) refrain from exercise during acute illness, 11) access supplemental oxygen at altitude as needed, and 12) seek prompt medical care when experiencing unusual distress.

The changes to the 2008 guideline began with recommendations from the National Athletic Trainer's Association. The National Athletic Trainer's Association (NATA) published a Consensus Statement (2007) entitled: *Sickle Cell Trait and the Athlete*. The purpose of the statement was to raise awareness of exertional rhabdomyolysis (explosive muscle breakdown) in sickle cell trait carriers and provide measures to reduce the risk of exertional collapse related to SCT. This statement is the basis for the NCAA's amendment to Guideline 3c. The NATA

Recommend[s] confirming sickle cell trait status in all athletes' pre participation physical examinations. As all 50 states screen at birth, this marker is a base element of personal health information that should be made readily available to the athlete, the athlete's parents, and the athlete's healthcare provider, including those providers responsible for determination of medical eligibility for participation in sports (National Athletic Trainer's Association, 2007).

In 2010, the NCAA adopted new SCT testing legislation. The NCAA developed a question and answer document to be utilized by NCAA Division 1 membership in explaining Proposal 2009-75-B. The following answer was written to the question, "Does NCAA Division 1 legislation require sickle cell trait testing?"

In Division I, legislation has been adopted that requires institutions, as part of the medical examination required before athletics participation, to include a sickle cell solubility test, unless documented results of a prior test are provided to the institution or the student-athlete declines the test and signs a written release. This legislation is effective as of August 1, 2010 and is applicable to student-athletes who are beginning their initial year of eligibility and student-athletes trying out for a team, including transfers. Returning student-athletes are not required to be given the test.

As can be seen, the evolution of the 1998 revision to the 2010 proposal was remarkable. The risk to the student athlete with sickle cell trait is of utmost concern. Although screening is mandated for all athletes, it is well-documented that in the United States, SCD/SCT primarily affects African Americans more than any other race or ethnicity (NIH, 2008). Therefore, it is necessary to examine policy that mandates sickle cell trait screening among intercollegiate athletes thoroughly and critically so that social justice issues (e.g., discriminatory practices based on race) will not surface as an unintended consequence of mass screening. This thorough and critical examination provides the basis for the understanding of the problem that this study will address.

### *Both Sides of the Controversy*

To properly understand the cause for concern about mandatory SCT testing and the necessity of an education program and intervention, it is imperative to have a critical discussion of key factors. First, there is risk to the athlete with SCT. It is debated whether or not the NCAA



came to the decision to mandate the screening of athletes too quickly. However, there is evidence of the risks of SCT to the athlete. These risks will be outlined.

Secondly, factors shaping the controversy surrounding NCAA mandated SCT screening will be discussed. The controversy will be explained as follows: 1) the history of SCT and negative consequences of genetics screening and policy that mandates SCT testing, 2) genetics exceptionalism, and 3) racism and its association with college athletics. Finally, the lack of knowledge of SCD/SCT will be discussed to justify the need for a SCT education program for coaches and athletes.

### *Reasons for Mandatory Sickle Cell Trait Screening*

#### *Sickle Cell Trait and Exercise.*

In general, sickle cell trait does not significantly affect health, limit physical activities, occupation, or life expectancy (NATA, 2007; Connes, 2008). Although, SCT carriers are able to practice certain aerobic activities, it seems that they may not be able to train or compete at the same high level as subjects with normal hemoglobin (Connes, 2008). An important potential complication of sickle cell trait is unexpected exercise-related death (ERD). It has been hypothesized that SCT carriers have lower aerobic ability than subjects with normal hemoglobin because within the RBCs, HbS has a lower affinity for oxygen than HbA (Connes, 2008). During exercise, the body's pH decreases and the temperature increases at the tissue level to facilitate oxygen delivery; these changes lead to higher concentrations of deoxygenated hemoglobin (Mitchell, 2007). Due to the lack of oxygen, sickle cells can "logjam" blood vessels and lead to collapse from ischemic rhabdomyolysis, the rapid breakdown of muscles starved of blood (NATA, 2007).

On the contrary, some authors believe that sickle cell trait carriers may have an advantage. It has been hypothesized that the low affinity of HbS for oxygen within SCT carriers' RBCs might cause repeated episodes of tissue hypoxia, causing exercising muscles to develop anaerobic capacity to compensate for the hypothetically low oxidative capacity (Bile, LeGallais, Mercier, et. al, 1996 & LeGallais, Lonsdorfer, Bogui, et al, 1989). SCT carriers have been shown to reach higher performance during a jump and reach test than control subjects (Hue, Julan, & Blanc, et al, 2002). SCT carriers have also been found not to be disadvantaged in extremely brief and intense exercise involving mainly alactic anaerobic metabolism (Connes, 2008). Although researchers have found that SCT carriers may have some athletic advantages, deaths have continued to prove that there are disadvantages to the SCT carrier as well.

*Deaths Due to Exertion in Sickle Cell Trait Carriers.*

Myriad controversy continues to engulf sickle cell trait and its relation to exercise related morbidity and sudden death (Mitchell, 2007). Individuals with the SCT are typically asymptomatic, with a record of sporadic cases of unexplained morbidity and mortality (Makaryus, Catanzaro, & Katona, 2007). The idea that healthy young people with sickle cell trait might suffer increased mortality from exercise was first suggested by observations of enlisted recruits in US Armed forces basic training. A military trainee with SCT suffered exercise related hypernatremia (greater than normal concentration of sodium in the blood) during training. He narrowly survived a critical illness that included acute renal failure. During a single summer, there were four exercise-related deaths among recruits at Fort Bliss, all of whom were black and had sickle cell trait, while no recruits with normal hemoglobin died (Kark, 2000).

The U.S. military tied sickle cell trait to sudden death during recruit basic training. Recruits with sickle cell trait were 30 times more likely to die during basic training. The main cause of death was a condition called rhabdomyolysis (rapid muscle breakdown)-and the risk of exertional rhabdomyolysis was about 200 times greater for those with sickle cell trait (NATA, 2007). In a recent review of non-traumatic sports deaths in high school and college athletes, by the National Athletics Training Association, the top four killers, in order of occurrence were: cardiovascular conditions, hyperthermia (heatstroke), acute rhabdomyolysis tied to sickle cell trait, and asthma (NATA, 2007).

In the past four decades exertional sickling has killed at least 15 football players. In the past seven years alone, sickling has killed nine athletes: five college football players in training, two high school athletes (one a 14-year-old female basketball player), and two 12-year old boys training for football. Of 136 sudden, non-traumatic sports deaths in high school and college athletes over a decade, seven (5%) were from exertional sickling (NATA, 2007).

Sickling collapse is not limited to football. It has occurred in distance racing and has killed, or nearly killed, several college or high school basketball players (two were females) in training, typically during “suicide sprints” on the court, laps on a track, or a long training run (NATA, 2007). Nearly all the deaths in college football have been at institutions that either did not screen for sickle cell trait, or had a lapse in precautions for it (NATA, 2007). Clarke (2006) conducted a study about SCT screening practices in 92 Division 1-A schools. The majority (64%) had established criteria for sickle cell trait screening in the pre-participation exam. Of these schools, 91% screened athletes with family history of sickle cell disease or trait, 76% screened African American Athletes, and 21% of these screened all athletes. Although screening can

bring about awareness of personal health, there are many concerns about performing these tests in mass. Hematologists', other medical professionals', and those who advocate for people with sickle cell disease or traits (hereafter referred to as 'the sickle cell community') concerns about mandatory SCT are as follows.

#### *Controversy Concerning Mandated SCT Testing*

Sickle cell screening programs have been scrutinized since the 1970s (Pemberton & Wailoo, 2006) because of their lack of sensitivity to issues of race. The recent change in NCAA Guideline 3c has been met with similar scrutiny. The sickle cell community is concerned that there may not be enough evidence of the association of sickle cell trait to sudden death in athletes to warrant this type of recommendation. Concerns about the recommendation leading to discrimination towards sickle cell trait carriers within college athletics are also at the forefront of this debate. These concerns are legitimated by the fact that the NCAA has developed policy that mandates SCT screening, yet has not developed policy that ensures the protection (from discrimination) of the athlete with SCT.

#### *Sickle Cell Legislation and Unintended Consequences*

In the 1970s, legislation was passed that mandated screening for SCD/SCT. The Sickle Cell Disease Control Act of 1972 (Public Law-92-924) (see Appendix D) was an outgrowth of a presidential initiative in 1972 and increased federal support for the treatment of and research of SCD and initiated SCD education and screening programs in the United States. This act increased the knowledge and awareness of SCD among African Americans as well as other ethnicities. However it also provoked many new controversies such as concerns about racism (Hill, 1994; Wailoo, 2001). More often than not, however, these laws were written and passed

without adequate attention being given to the stigmatizing of those people with the disease and those who carry the sickle cell trait (Wooley & Peters, 2010).

The result of mass sickle cell screening along with mandatory state screening laws, led to concerns about racism among African Americans. Researchers have suggested that the early sickle cell screening programs may have been criticized because of the perceived racism surrounding the disease (Wailoo, 2001). Atkin and Ahmad (1998) stated that public recognition of sickle cell disorders in the United States was accompanied by the suggestion that the existence of SCD among African Americans proved genetic inferiority.

Further criticisms of early sickle cell screening programs included their lack of sensitivity to issues of race, controversy surrounding the accuracy and validity of the early screening tests; and inadequate protection of the patients' rights (Markel, 1992).

#### *Negative Consequences of Screening*

Screening asymptomatic individuals is common and has become more prominent as prevention has come to the forefront in medical practice. Generally, mass population screening has been conducted for four purposes: pre-symptomatic detection of disorders for which effective treatment is thought to be available; reproductive counseling; research, including studies of prevalence or natural history, or to recruit individuals into experimental treatment studies; and inclusion or exclusion particularly for decisions regarding insurance employment (Fost, 1992).

Screening, although well intentioned, has resulted in unintended consequences such as prejudice against those who have taken part in asymptomatic testing. Risks of widespread screening often include confusion and discrimination (Fost, 1992). Confusion about sickle cell

trait is common, and typically involves a failure to understand the difference between sickle trait, the carrier state, and sickle cell disease, the homozygous condition or a failure to understand basic elements of probability and reproductive risks (Fost, 1992). Discrimination based on genetic testing has surfaced in various forms. In 1969, Linus Pauling said,

I have suggested that there should be tattooed on the forehead of every young person a symbol showing possession of the sickle-cell gene or whatever other similar gene, such as the gene for phenylketonuria, that has been found to possess in single dose. It is my opinion that legislation along this line, compulsory testing for defective genes before marriage, and some form of public or semi-public display of this possession, should be adopted.

Pauling was a scientist who understood the ramifications of a diagnosis of sickle cell disease. This statement was not likely made with the intent to discriminate against individuals with sickle cell disease. However, the proposed solution, although well-intentioned, would almost definitely cause discrimination against these individuals.

Employers have violated Title VI of the Civil Rights Act of 1964, which prohibits employment discrimination based on race, color, religion, sex, and national origin, (United States Department of Justice, 2010) by discriminating against people based on a genetic trait that disproportionately impacts a particular protected group, such as sickle cell disease in African Americans or Tay-Sachs disease in Ashkenazi Jews (Miller, 1998). Many states once required sickle cell screening as a condition of entry into elementary school (Fost, 1992). This served no apparent public health purpose nor did it offer any clear benefit to prospective students, because the vast majority with sickle cell disease would already have been diagnosed

by that age, and those with sickle trait had little to gain from genetic counseling while in elementary school. Prior to 1981, the United States Air Force Academy excluded African-Americans with sickle cell trait because of concerns over service connected disability (Scott, 1982). A New York State law ordered that all persons who were not Caucasian, Indian, or Oriental, be tested for sickle cell trait before being allowed to obtain a marriage license (Markel, 1992).

Each of these discriminatory practices was unfounded and led to inequity for the individuals, primarily those who are African American, who tested positive for sickle cell trait. Screening for SCT and the provision of simple precautions may prevent deaths and help the college athlete with SCT thrive in his or her chosen sport (Connes, 2008). However justifications for mandatory screening should be carefully scrutinized (Fost 1992).

The NCAA's recent adoption of SCT screening policy has been met with controversy from the sickle cell community. Knowledge of the history of SCT screening and potential negative consequences of genetic testing and disease screening are the basis for the concern that athletes with SCT will be discriminated against. The criticism of inadequate protection of patients' rights leads to the discussion of genetic exceptionalism.

#### *Informed Decision Making and Genetic Exceptionalism*

There is concern among scientists, physicians, genetics counselors, and their patients that individuals whose genetic characteristics are predictive of serious disease will face discrimination (Hellman, 2003). If genetic testing is necessary to determine a college athlete's SCT status, then the topics of informed decision making and genetic exceptionalism are central to this issue. The patient-provider relationship is evolving from paternalism to partnership

(Emery, 2001). The internet and various other social media have offered the inquisitive patient a wealth of resources concerning personal health issues, allowing them to make more informed decisions. Informed decision making has been a vital aspect of policies related to testing for conditions such as the Human Immunodeficiency Virus (HIV). The Centers for Disease Control (MMWR) (2006) defines informed consent for HIV testing as “a process of communication between patient and provider through which an informed patient can choose whether to undergo HIV testing or decline to do so”. Elements of informed consent include providing oral or written information concerning HIV, risks and benefits of testing, implications of the HIV test result, how the results will be communicated, and the opportunity to ask questions. HIV testing brought about policies that included pre/post test counseling, anonymous testing, and strict protections of confidentiality (Lazzarini, 2001).

Informed decision making is debatably more difficult in genetic than for non-genetic diseases such as HIV (Emery, 2001;Lazzarini, 2001; Green, 2003; Sarata, 2008). Genetics has been said to be “exceptional” based on the premise that genetic information is unique and merits both special and differential or exceptional treatment (Sarata, 2008). Informed decision making in genetics is more difficult and genetics information is said to be exceptional for several reasons. 1) Genetics tests can have broader implications (for individuals, family, and society) than non-genetic results. 2) Carrier status for autosomal recessive conditions (e.g. sickle cell trait) may be difficult for patients to conceptualize. 3) Genetics test results are predictive of future disease, 4) Genetics conditions are vertically transmitted from parent to child, 5) Genetics information can be utilized for purposes other than what is intended. 6) Genetics information is of interest to third parties such as employers and insurance companies,



7) Genetics information can be stored and removed after many years, and 8) Genetics information can be utilized to discriminate against individuals (Emery, 2001; Lazzarini, 2001; Green, 2003; Sarata, 2008).

Green (2003) counters some of these exceptions. The argument that genetics information can predict a person's future is countered by saying that HIV can be predictive of Auto Immunodeficiency Syndrome (AIDS), a tuberculin skin test can be predictive of tuberculosis, and high blood pressure can be indicative of future heart disease. The debate that genetic information can be utilized more so than non genetic information to discriminate against individuals can hardly stand when compared to the discrimination that individuals with HIV and other non-genetics diseases have faced (Green, 2003).

Studies have examined the perspectives of the general public concerning the exceptionalism debate (Planting, Natowicz, Kass, Hull, Gosting, & Fadon, 2003; Diergaarde, et al, 2007). It was found that the general public did not view genetics information differently than non-genetics information. Study participants felt that all medical information should be protected. It was also noted that the fact that the information was genetic was not what made it sensitive information. It was the societal stigma that is associated with the disease or information that made it sensitive. Diergaarde et al (2007) also found that there was no difference in these views between those who had genetic versus non-genetic conditions.

Specific to SCT, lack of knowledge is a barrier to informed-decision making concerning SCT testing (Asgharian & Anie, 2003). In a study of African American women, Hill (2004) noted that women "obfuscate" or obscure, confuse, and complicate SCT information subconsciously in order to protect their reproductive autonomy (control over reproductive decisions such as

mate selection). Asgharian and Anie (2003) examined views of 35 female carriers of SCT. It was found that not every participant had clear understanding of what their SCT status actually meant. The study also found that obstacles to informed decision making included 1) inadequate knowledge of SCD/SCT, 2) Concern about what others may think if the subject of SCT was raised, and 3) Number of complications expected when facing the issue directly.

Athletes who have no prior knowledge of SCD/SCT, or who have fears associated with testing are not likely to understand the benefits of testing. It is important to consider important features of genetic decision making as noted by White (1999): 1) Every genetic decision is unique, based on individual responses to risk and uncertainty in the context of personal values and circumstances. 2) The consequences of genetic decisions are not confined to individuals, but may affect family members directly and society indirectly. 3) Advances in the diagnosis and treatment of genetic disorders may rapidly change perceptions of what counts as a genetic disease or disability.

No information, regardless of its genetic or non-genetic nature, should be utilized to “rob an individual of hope, deny them services, benefits, or opportunities” (Lazzarini, 2001). The necessity of genetics tests should be carefully assessed. Green (2003) lists 4 domains that should be considered when determining the effects of genetic testing on a patient. 1) The degree to which the information can be stigmatizing. 2) The effect of the test results on others. 3) Availability of effective interventions, and 4) the complexity involved in interpreting test results.

In the current study, it was important to consider each of these features. Every athlete’s perception of SCT testing was unique and based upon knowledge, ethnicity, personal

experience, and family history. The consequences of testing positive for SCT are not confined to the athlete, but may affect future goals of obtaining professional athlete status as well as the ethnic composition of sport if racial discrimination occurs. The results may also affect families as a positive SCT test result may reveal undisclosed information about paternity. Perceptions of what counts as a genetic disease or disability has changed recently in college athletics. NCAA Guideline 3c advanced from not recommending screening for athletes to the policy of screening for all athletes and provision of precautions for the athlete with SCT.

A link exists between the exceptionalism debate in genetics and the notion of racial exceptionalism as is described in Delgado and Stefancic (2001). The authors note that race is exceptional because a group's history is so distinctive that placing it at the center of analysis is warranted.

#### *Race, Racism, and College Athletics*

The link between sickle cell disease, race, and athletics necessitates a discussion of race. Race is a social construct; a "cultural creation" (Johnson, 1997; Delgado & Stefancic, 2001). As early as the 1800s, medical professionals attempted to document, scientifically, the inferiority of African Americans. Empirical evidence was produced that justified racial differences and determined that the races were not equal and could not possibly experience similar health profiles nor obtain equal positions in society (Krieger, 2002). Waller (1998) describes racism as "an individual's negative prejudicial attitude or discriminatory behavior toward people of a given race or institutional personnel, policies, practices, and structures (even if not motivated by prejudice) that subordinate people of a given race" (p. 47).

Sports studies have been criticized because they overlook the issue of race (Hylton, 2005). Harper (2005) examined the issue and found that African American athletes perceived that they were treated differently than their white counterparts by members of the athletic department. They also felt that they had less opportunity to rise to leadership positions within athletics.

King, Leonard, and Kutz (2007) set out to bring “White power” to the forefront of sports studies. They argued that athletics remains a highly racialized and intensely stratified domain in the United States” (p.5). The study discusses three types of white power in sport: 1) Persistent, 2) resurgent, and 3) veiled. Persistent white power was defined by the authors as “antiquated ideologies and abolished institutions such as scientific racism, Jim Crow, and apartheid” (p. 4). To illustrate persistent white power, the authors cited examples of racism towards African Americans across three decades. Examples utilized were hate letters from white supremacists written to Henry Aaron as he approached Babe Ruth’s homerun record (1973), and letters sent to black NFL players threatening harm if they did not stop having relationships with white women (2003). These examples were given to challenge the beliefs that racism no longer exists on America’s playing fields and in society.

The second form of White power discussed was resurgent White power. The authors state that resurgent White power is a combination of racialized theories and projects such as white supremacism, white nationalism, and white separatism that share common beliefs such as: a) “essentialized notions of racial difference, b) a conviction that such differences threaten Whites and White culture, c) a desire to reestablish White dominance, and, e) a tendency to express such positions in coded, sanitized language often appropriated from mainstream, and

even progressive, political movements (Ferber, 1998; King & Leonard, 2004).” (p. 6) The authors explain that resurgent White power is often expressed electronically either online or through television media.

The third type of White power discussed is veiled white power. The authors define veiled White power as a “new racism” (p. 7). They state that “Whites dematerialize White power, construct a color-blind world and take pleasure in secure differences” (p. 7). Each of these contributes to the new racism or a type of hidden White supremacy. The authors state that the three types of White supremacy (perceived, resurgent, and veiled) contribute to the use of sport as a vehicle to reactivating the racial anxieties of whites fearful of lost power. White power reemerges through arguments that black male dominance in sports such as football and basketball have led to the marginalization of White male athletes and subsequently the erosion of White male power and privilege.

Brooks and McKail (2008) argue that it is the Black male who is marginalized in college sport. The authors discuss the marginalization of the Black male basketball player through the use of the theory of a preferred worker. Preferred workers are those who are hired based on race, gender, and socioeconomic status. They are preferred because they produce a product or increase revenue for the employer at minimal cost. The authors cite the history of African Americans in sport and highlight that Black presence on White teams increased when White owners saw African American athletes’ athletic potential and began to recruit them.

Low graduation rates for Black male athletes and large television and marketing revenues are given as evidence that Black males are essentially laborers. The authors question why Blacks are predominate in football and basketball and not other sports. They ask why

Black males would be better at these sports than other sports where white males exhibit similar athleticism. The authors conclude that Black athletes typically come from poor neighborhoods and have low socioeconomic status. They are subjected to an 'informal curriculum' through the media that tells them what they should become. Therefore, they feel that the only way to escape these circumstances and to have true fame and fortune is to play basketball. This is described as the "push-pull effect" where: "young Black men felt a push from their communities to pursue basketball, while at the same time, there was a pull from colleges, universities, and professional ranks, who wanted to win more games and improve their profitability" (p. 378). The authors state that the money and power differential between Black male athletes (college and professional) contributes to the marginalization of the black males in sport. They conclude that it is not the Black male's natural ability that causes their domination of basketball, but their "socio-economic position, vulnerability, and usefulness to larger structural interests"(p. 382). The history and negative consequences of genetics screening, the idea of genetic exceptionalism, and racism in general as well as in college sport, shape the controversy surrounding NCAA mandatory screening. These issues will be coupled with the issue of lack of knowledge of sickle cell trait to illustrate the need for a sickle cell trait education program for athletes and coaches.

#### *Knowledge and Attitudes Regarding Sickle Cell Trait*

Studies have shown that African Americans lack fundamental knowledge about sickle cell (Boyd et. al, 2005; Ogamdi, 1994; Catz et al, 2005; Treadwell, 2006). Since sickle cell disease predominantly affects African Americans, it is important that their knowledge base of

signs, symptoms, and genetics be enhanced. Boyd et. al (2005) and Ogamdi (1994) illustrate the lack of awareness and need for education among African Americans.

Boyd and her colleagues (2005) conducted a cross-sectional telephone survey of 264 African American women ages 18-30. The women were given a survey that tested their general knowledge of sickle cell, genetics, management, and educational resources. Thirty percent (30% or 102) of the women were unable to complete the survey because they were completely unaware of sickle cell disease. Of the 162 women who were able to complete the survey, 91% of the women believed that sickle cell disease was a hereditary blood disorder, however only 9.3% understood the inheritance pattern. Also, 11% of the women were unaware of their sickle cell trait status (Boyd et. al, 2005).

Ogamdi (1994) conducted a study among college students. Three-hundred-thirty-four (334) students at a predominantly African American university in Texas were surveyed concerning sickle cell knowledge. It was found that knowledge about sickle cell disease was inadequate. Eighty-one percent of the participants did not know the genotype that describes sickle cell disease (SS) and more than 60% of the students did not know the disease could be prevented if individuals made responsible reproductive choices (Ogamdi, 1994).

Catz et al (2005) found that 35% of participants responded “nothing” to the question “What have you heard about genetic testing?” Participants who had heard about genetic testing felt that genetic testing was 1) good because it leads to prevention or to a better degree of preparation in case of disease, and 2) a double-edged sword, since it can be good for prevention, but it can also be used unethically; can cause too much anxiety if the tests are diagnostic, or can provide a false reassurance if tests are negative. Participants in the most

educated black American group raised the most concerns against human cloning and abortion, and also expressed concerns about whom would have access to genetic information, 'genetic' discrimination, and how genetics could be used to create a selective society (Catz, 2005).

Treadwell et al. (2006) conducted a mixed methods study to determine knowledge and perceptions about SCT and SCD, to evaluate the usefulness of different sources on information about SCD and SCT, and to determine participants' knowledge of personal SCT status. Focus groups and interviews were administered to participants. Treadwell et al. (2006) found emergent themes that included, a) limited awareness of SCD and SCT, an emphasis on the benign nature of SCT rather than on future implications (i.e., reproductive decision making), and the need for public health education campaigns about SCD and SCT involving media strategies. The majority of individuals who completed the survey (86.2%, n=243) had correct general knowledge about the genetics and severity of SCD, but only 16% (n= 45) knew their own carrier status.

As a result of common misconceptions regarding SCT, most individuals with the condition are generally not informed regarding the possible consequences of certain activities such as venturing to high altitudes or participating in overly exertional physical activities in high temperature without sufficient hydration (Connes, 2008), and many athletes do not know their sickle cell trait status, rendering self-report of having the trait in a questionnaire unreliable (National Athletic Trainer's Association, 2007).

The link between sickle cell trait screening, knowledge of SCT, health beliefs, racial discrimination, and possible policy implications warrant the need to use both the Health Belief



Model and Critical Race Theory as foundations for the current study. It was also necessary to utilize a rigorous framework that addressed multilevel factors to inform the intervention.

### Theoretical Framework

#### *PRECEDE-PROCEED Model of Program Planning*

PRECEDE-PROCEED (PRE-PRO) is not a theory. It is a planning model that provides a framework for identifying intervention strategies. The model views health behavior as influenced by both individual and environmental factors. The PRE portion of the model is an educational diagnosis. PRECEDE stands for predisposing, reinforcing, and enabling constructs in educational/environmental diagnosis and evaluation. Predisposing factors are those that motivate or provide the logic behind behavior. These include knowledge, attitudes, and beliefs. Enabling factors allow individuals to act upon their pre-established beliefs. These include available resources and supportive policies. Reinforcing factors encourage behavior and include social support, praise, and symptom relief.

During the PRE phase, researchers utilize various methods (e.g. key informant interviews, focus groups, surveys, literature reviews) to assess community needs as well as to determine the context in which the intervention will take place. Policy implications are also assessed to ensure an ecological diagnosis of the problem. Practitioners use individual, interpersonal, or community level change theories to classify determinants of behavior into predisposing, reinforcing, or enabling factors. This study utilizes an individual theory, the Health Belief Model (Strecher & Rosenstock, 1997) to accomplish this task.

### *Health Belief Model*

Health beliefs and attitudes influence the way people approach new knowledge, learning, and decision making (Catz et al, 2005). The Health Belief Model (HBM) was developed initially in the 1950s by a group of social psychologists to help explain why individuals failed to participate in programs to prevent or detect disease (Strecher & Rosenstock, 1997). The HBM is a value expectancy theory meaning that the desire to avoid illness (value) interacts with the belief that a health action, like SCT screening, would prevent illness (expectancy). Perception is an integral part of this theory. Perceived susceptibility (an individual's opinion on chances of getting a condition), perceived severity (an individual's opinion of how serious a condition or its consequences are), perceived benefits (an individual's opinion about the benefits of the action to reduce risk), and perceived barriers (an individual's opinion of the real and perceived costs of the recommended action) are all constructs of the Health Belief Model.

Gustafson (2006) utilized the HBM to examine how health beliefs and education influence acceptance of genetic screening for sickle cell trait. African American women of childbearing age, being seen in a busy prenatal clinic were surveyed. It was determined that a short education session increased knowledge of SCT and acceptance of screening. Perceived severity of sickle cell trait was high among the women. However, perceived susceptibility to SCT was low because many of the women stated that sickle cell [disease] did not run in their families indicating a possible lack of knowledge of SCT. Perceived benefits of sickle cell trait testing were high, and perceived barriers to testing were low. It was concluded that the women frequently did not perceive themselves to be at risk for having a child with SCD regardless of knowledge.

In a mixed methods study, Stewart (2007) utilized the HBM to examine African American college students' knowledge and attitudes towards SCD and SCT testing. College students (n=191) ages 19-30 were surveyed. The majority of participants (85.3%) had positive attitudes towards SCD carrier testing. It was determined that neither carriers of sickle cell trait nor non carriers perceived the SCT as a severe or serious condition. Non-carriers stated that in comparison to other conditions such as HIV, SCT was of little concern and was only of concern when making reproductive decisions.

Genetic conditions similar to SCD have been studied utilizing the HBM. The purpose of a study by O'Connor and Cappelli (1999) was to determine the factors that influence decisions to test for cystic fibrosis (CF). The CF Carrier Testing Survey was used to measure knowledge about the disease, possible changes arising from carrier testing, attitudes toward genetic testing and behaviors after carrier screening. Constructs of the health belief model were used to determine perceived benefits, barriers, susceptibility and severity as they relate to CF. It was found that similar to sickle cell disease, many individuals in the study population had not heard about CF. Also, it was found that increased perceived severity had an inhibitory effect on testing decisions. Therefore, utilizing scare tactics to influence people to test for genetic disorders may be contraindicated (O'Connor & Cappelli, 1999).

### *Critical Race Theory*

Critical Race Theory (CRT) is a conceptual lens used to examine racism, racial (dis)advantages, and inequitable distribution of power and privilege within institutions and society (Bell, 1987; Delgado and Stefancic, 2001). It is also used to analyze racial factors that may contribute to or result from policy implementation. Delgado and Stefancic (2001) illustrate

that whiteness is often associated with innocence and goodness: Brides wear white to signify purity. Snow White is a fairytale of virtue receiving its' just reward. A white light is often said to be seen as a projection of hope for a positive and benign spiritual force. Blackness, however, is associated with doom. Villains often wear black. People are said to be black balled or black listed when friendships are broken, and gloom is associated with blackness. Society describes people as non-white as if white is normal and blackness is not.

CRT has an activist dimension. It not only tries to understand a social situation, but to change it. The basic tenets of CRT include: a) racism is "ordinary", the usual way a society does business; b) interest convergence (the majority (i.e. Whites) will advance a person of color only if their own best self interest is served); c) race is a social construction (race and races are products of social thought and relations); d) differential racism (society racializes minority groups at different times in response to the shifting needs of the labor market); and e) unique voice of color (minorities should apply their own voice to the topic of race and racism). Each of these was utilized in this study with the exception of differential racism.

CRT challenges the notions of colorblindness, merit, and racial equity, and also tests the innocence of self-proclaimed white liberals and sparks awareness that leads to social justice and the advancement of people of color (Crenshaw, Gotanda, Peller, & Thomas, 1995). According to Donnor (2005), CRT offers a way "to better recognize and more fully understand the forces that have constructed a system in which African American male athletes are cheered on the field by wealthy alumni and powerful fans while at the same time denied opportunities to earn the degree that could lead to wealth and power of their own" (p. 63).

Critical race theory when applied to sport is often associated with educational outcomes of black athletes. Harper (2009) utilized CRT, particularly the construct of interest convergence, to examine education outcomes of student athletes at community colleges as well as to demonstrate how community colleges would benefit from increasing the transfer rate among black male students. He states that interest convergence (advancing a person of color only if one's own best self interest is served) plays a critical role in interactions between educational institutions and African American athletes for the following reasons: 1) Black males are interested in transferring to professional sports, 2) Transfer of African American athletes to four-year universities increases the overall transfer rate for the university, 3) Transfer of African American Athletes to four-year universities increases the reputation of the university, 4) Coaches who are held accountable for student success benefit when they are successful, and 5) Community colleges should recognize that there is a possibility that these players could be drafted by the NBA or NFL and give back to the colleges.

Singer (2009) utilized CRT to examine the perspectives of four African American football athletes at a predominately white institution of higher education. The athletes participated in a focus group and individual interviews. The goal of the study was to determine participants' perspectives on institutional integrity ("the athletic program's commitment to the educational interests of college students as expressed through their structures, functions, and activities" (p. 102)). Themes that emerged from this study were: a) [The need for] African American role models in leadership positions, b) lack of financial support [for African American athletes], and c) [The need for] a platform [for athletes] to voice concerns. The third theme, platform to voice concerns, is most relevant to the current study. Athletes reported that they "appreciated the

opportunity to be included in the dialogue on strategies to bring about change and institutional integrity in college athletics” (p. 110). Storytelling is an important aspect of critical race. This study illustrates that athletes want to be included in critical assessments of organizational and institutional change within college athletics.

Singer (2005) also utilized CRT to examine these participants’ perspectives of racism on campus. Two themes emerged: 1) lack of opportunities to participate in major decision-making roles within sport and, 2) being treated differently. Athletes perceived that they were given classes that they did not need resulting in longer time at the university; whereas white students were given the exact classes they needed to complete their education in a timely manner. A participant also expressed that few blacks played the position of quarterback because it was a decision-making position on the team- and blacks aren’t given that opportunity. Participants also concluded that they were not given as many opportunities to make mistakes (i.e. getting a DUI) outside of college athletics as White students.

#### Need for Study

Harper (2009) concluded that “perhaps nowhere in higher education is the disenfranchisement of black male students more insidious than in college athletics”. This study aims to bring awareness to the possibility of social injustice that may be unintentionally brought upon African American athletes who are determined to have the SCT when tested under the NCAA policy. Due to the possible social implications that may result from this policy (i.e. discrimination), it is important that a comprehensive program is developed that will educate coaches and athletes about SCT from pre-participation screening to sickle cell trait diagnosis. It is also necessary to determine organizational and policy factors that influence this issue as well.

## Chapter Summary

The issue of SCT and extreme exertion has been contemplated for decades. The United States Military was the first to discover a link between SCT and death. Efforts at mass screening for SCT were scrutinized because of issues of discrimination based upon race. The NCAA has suffered similar scrutiny because of the apparent lack of attention to social justice issues surrounding mandatory screening. This chapter discussed the issues of race, informed decision making, genetic exceptionalism, and lack of SCT knowledge based upon a foundation of principles from the Health Belief Model and Critical Race Theory.

The following chapter will discuss the mixed methods design of the study. It also includes a discussion of the sampling procedures, data collection procedures and instruments, and data analysis procedures.

## CHAPTER 3

### RESEARCH METHODS

#### Data Collection and Analysis Paradigm

Data collection and analysis for the current study were based upon a critical theory approach. Critical theory approaches data collection and analysis with a clear agenda of exposing power, economic, and social inequalities (Patton, 2002). It aims to critique society, raise consciousness, and change the balance of power in favor of those less powerful. This approach connects theory and action (Patton, 2002).

The undeniable link between racism and the history of sickle cell anemia, African Americans, college athletics, and the lack of protection for athletes within NCAA policy warrants the need for a critical theory approach to data collection and analysis within this study. Controversy over the NCAA's recommendation 3C stemmed from fears of discrimination against those who carry the sickle cell trait. If this discrimination were to occur, it would be a social injustice. Research that is designed based upon a critical approach is collected and analyzed in such a way that social inequalities are not only revealed, but an attempt is made to right them (Patton, 2002). The aim of this study is not merely to reveal social injustices that may take place in college athletics, but to educate and empower athletes, coaches, and athletic trainers, so that social injustices may be prevented.

#### The Researcher

The researcher has sickle cell disease (not just SCT) and has been directly affected by discrimination related to sickle cell disease. The researcher is extremely passionate about social justice issues surrounding sickle cell disease and trait. Therefore, this study was taken on in an



effort to utilize the researchers inherent expertise to help right any social injustices that might be directed towards those who carry sickle cell trait or sickle cell disease who may be less fortunate. The combination of the researcher's doctoral level education, and personal experience with sickle cell disease was utilized as a foundation and catalyst for this study. Reflexivity as is described by Lincoln & Guba (1985) was consistently utilized throughout this process to minimize bias and will be discussed in detail later in this chapter.

### Mixed Methods Design

The critical nature of the study was addressed by utilizing a mixed methods design. Researchers have increasingly turned to mixed-method techniques to expand the scope and improve the analytic power of their studies (Sandelowski, 2000). Mixed-method studies entail concrete operations at the technique level of research by which "qualitative" and "quantitative" techniques are used together and either remain distinct design components, or are explicitly integrated (Caracelli & Greene, 1997).

The type of mixed methods research design that was employed in this study is the sequential explanatory mixed methods design. In a sequential explanatory mixed methods study, the researcher collects and analyzes quantitative data in the first phase and then collects qualitative data in a second phase in order to explain quantitative findings (Creswell, 2009).

#### *Justification of Sequential Explanatory Mixed Methods*

Neither a quantitative nor a qualitative approach alone would have yielded the desired results of the study. The purpose of quantitative data is to generalize; whereas, the purpose of qualitative data is to understand (Patton, 2002). Quantitative findings were essential to generalize the knowledge, attitudes, and perceptions of this particular group of athletes.

However, explanations of perceptions and knowledge of the athletes and coaches experiences in their own words, which is essential to critical study, were only captured through qualitative data collection and analysis. The combination of these methods enhanced the rigor as well as the usefulness of the study.

### Theoretical Framework

PRECEDE-PROCEED (PRE-PRO) (Green & Kreuter, 1999) was the planning model that provided the framework for identifying intervention strategies in this study. Only the PRE phase assessments were utilized. During the PRE phase, the researcher utilized various methods (e.g. key informant interviews, focus groups, surveys, literature reviews) to assess athlete needs as well as to determine the context in which the intervention would take place. PRE assessments were used to organize research questions as well as to group questions on the survey and the focus group interview guides. They were also utilized as organizational categories (e.g. families) when analyzing data using the Atlas.ti qualitative data analysis package.

The Health Belief Model (HBM) as well as Critical Race Theory (CRT) were utilized as the theoretical foundations for this study. Questions for the survey (see Appendix G) and the interview guides (see Appendices H-J) were developed based on the Sickle Cell Disease Assessment Survey (Stewart, 2007), a literature review of HBM, CRT, as well as SCT and its relation to NCAA sports medicine guideline 3c. The Sickle Cell Disease Assessment Survey (Stewart, 2007) was developed based upon the Knowledge and Beliefs about Cystic Fibrosis Scale (Surh, Cappelli, McDonald, Mettler, & Dale, 1994; Oconnor & Cappelli, 1999); *The Management of Sickle Cell Disease Publication* (National Heart, Lung and Blood Institute, 2002);

the Attitudes about Tay Sachs Disease and Cystic Fibrosis Carrier Testing Scale (Barlow-Stewart et al, 2003), the Perceived Severity Subscale (Henneman et al., 2001), and the Health Orientation Scale (Wooldridge & Murray, 1988). It was utilized as a guide for survey development in this study. However, questions were changed to fit the participants as well as context of the current study. Reliability and validity of these instruments are illustrated in Appendix L (Stewart, 2007).

Constructs of the HBM were utilized to determine if perception about susceptibility, severity, benefits, and barriers of SCD/SCT differed among ethnicities and were also utilized to determine the athlete's perceptions of sickle cell trait testing. CRT was utilized to formulate questions concerning racism and social injustice to determine if athletes of one ethnicity perceived the implications of this recommendation to be more severe than another ethnicity.

### Conceptual Model

The theoretical foundations were utilized to formulate the conceptual model (see Figure 2) for the study. Critical Race Theory was the conceptual lens by which the data were collected and analyzed. The Health Belief Model was utilized to examine the knowledge, attitudes, perceptions, and behaviors of two of the four study populations-athletes and coaches. The athletic trainer and hematologist were interviewed for current sickle cell trait screening practices and medical knowledge of sickle cell trait respectively. PRECEED-PROCEED (Green & Kreuter, 1999) was the program planning model that was utilized to determine athletes' and coaches' knowledge, attitudes, beliefs and perceptions as well as to perform a social assessment and situational analysis. Data collection from the athletes, coaches, athletic trainer

and hematologist led to the outcome which was informing a SCT educational intervention for athletes and coaches.

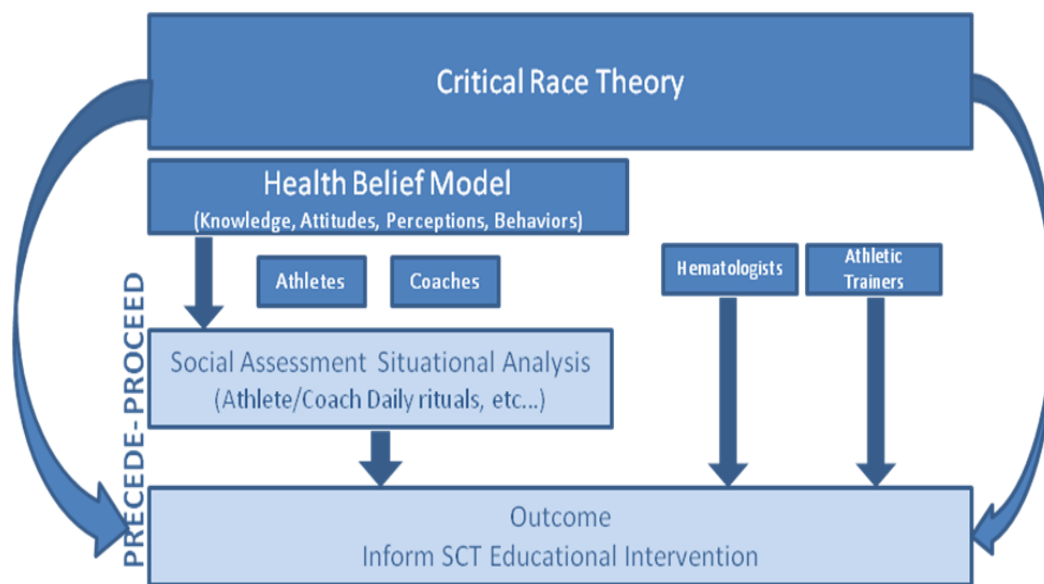


Figure 2: Conceptual Model for the Study

### Study Context

This study took place on the campus of Georgia Southern University. Founded in 1906, this regional university is located in the city of Statesboro, Bulloch County, Georgia. The university is classified as a doctoral/research institution by the Carnegie Foundation for the Advancement of Teaching and is a member of the University System of Georgia (Georgia Southern University, 2010). As the largest and most comprehensive research institution in the central coastal Southeast, the University is a residential campus of nearly 20,000 students. As of fall semester 2009, 29.9% (4,981) were minorities with 22.1% or 3,874 being African American.

Georgia Southern University is recognized for a nationally competitive athletics program. The University's 15 Division I teams compete in the Southern Conference. The university is recognized for obtaining six NCAA I FCS (formerly Division I-AA) football national

championships and NCAA tournament participation in men's and women's basketball, baseball, golf, women's tennis and volleyball (Georgia Southern University, 2010). Georgia Southern University's highly acclaimed history in athletics and its commitment to research as well as its students, make this an ideal setting for this study.

### Research Questions

Tables 3 and 4 illustrate the research questions and how they were utilized to answer quantitative and qualitative questions within the study. The research questions were aligned with the first four phases of the PRECEDE-PROCEED model (Green & Kreuter, 1999) of program planning and are as follows:

#### Overarching Research Question

What are the necessary components of the S.C.OR.E. Intervention that will be developed to educate intercollegiate athletes, as well as their coaches, about sickle cell trait from pre-participation screening to sickle cell trait diagnosis? The answer to this question was determined by answering a series of sub-questions that were aligned with the first four phases of the PRE-PRO model of program planning. The educational/ecological assessment was the primary phase utilized in the determination of necessary components of the intervention. This phase was primary because it included an analysis of the knowledge, attitudes, and perceptions, as they relate to SCT, of athletes and coaches. The remaining phases were secondary assessments and were utilized to determine the context in which an educational intervention for athletes and coaches would be set.

Table 3  
*Research Questions: Educational and Ecological Assessment*

Research Questions	Quantitative Hypotheses
What are the predisposing, enabling, and reinforcing factors that influence coaches and athletes' outlook on SCT testing?	<p>Hypothesis 1: Knowledge of SCT is not associated with athlete outlook on SCT testing</p> <p>Hypothesis 2: Perceived risk of having SCT is not associated with athlete outlook on SCT testing</p> <p>Hypothesis 3 : Perceived importance of knowing he/she has SCT is not associated with athlete outlook on SCT testing</p>
What are the predisposing, enabling, and reinforcing factors that influence coaches and athletes' outlook on NCAA guideline 3c?	<p>Hypothesis 4: Knowledge of NCAA 3c is not associated with athlete outlook on NCAA 3c.</p> <p>Hypothesis 5: Perception that NCAA 3c might result in athletes with SCT being treated unfairly is not associated with athletes' outlooks on NCAA 3c</p> <p>Hypothesis 6: Athletes' perceptions of receiving less playing time if he/she was diagnosed with SCT is not associated with outlook on NCAA 3c</p>
Do the predisposing, enabling, and reinforcing factors that influence coaches and athletes' outlooks on SCT and NCAA guideline 3c differ among ethnic groups?	<p>Hypothesis 7: Knowledge of SCT will not differ among ethnic groups</p> <p>Hypothesis 8: Perceived risk of having SCT will not differ among ethnic groups</p> <p>Hypothesis 9 : Perceived importance of knowing he/she has SCT will not differ among ethnic groups</p> <p>Hypothesis 10: Knowledge of NCAA 3c will not differ among ethnic groups</p> <p>Hypothesis 11: Perception that NCAA 3c might result in athletes with SCT being treated unfairly will not differ among ethnic groups</p> <p>Hypothesis 12: Athletes' perceptions of receiving less playing time if he/she was diagnosed with SCT will not differ among ethnic groups</p>

Table 4

*Research Questions: Social Assessment and Situational Analysis, Epidemiological Assessment, and Intervention Alignment and Administrative and Policy Assessment*

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**Social Assessment and Situational Analysis.**

What happens during a pre-participation physical?

How are athletes educated about health information discovered in pre-participation physicals?

How do athletes want to be educated about information received on pre-participation physicals?

What concerns do athletes have about health issues being revealed in pre-participation physicals?

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**Epidemiological Assessment**

What are the genetic, behavioral and environmental factors that are associated with sickle cell trait and the intercollegiate athlete?

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**Intervention Alignment and Administrative and Policy Assessment**

What capabilities and resources are necessary to develop an intervention that will educate intercollegiate athletes, as well as their coaches, about sickle cell trait from pre-participation screening to sickle cell trait diagnosis?

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The following sections will outline the survey, focus groups, and in-depth interviews as well as a rationale for the use of each method. Following the outline of sections, the qualitative and quantitative methods will be integrated with the research questions as well as the PRECEDE-PROCEED planning model to display a clear representation of how each of the individual phases intertwine within the current study.

#### Phase 1: Quantitative Research Methods

The quantitative portion of the study utilized a survey as the data collection method. The purpose of surveys is to generalize from a sample to a population so that inferences can be made about some characteristic, attitude, or behavior (Creswell, 2009). Information found in the literature (Littleton, 2007; Li et al, 2008; Fan et al, 2010; Lewis et al, 2009; Passmore, et al, 2002) served as a basis for survey development and administration in the current study. This study was reviewed and subsequently approved by the Institutional Review Board (IRB) at Georgia Southern University.

## Participants

The eligibility requirements to participate in this study were: being male or female college students 18-24 years of age, currently attending Georgia Southern University, and current members of the intercollegiate athletic teams. Participants were recruited from the approximately 270 athletes who were on intercollegiate athletic teams during the summer of 2010.

Sampling was not done in the quantitative portion of the study because all athletes were surveyed. Therefore, the study was a census. A census is a study where all individuals in a population are selected for measurement (Levy & Lemeshow, 1999). Since the total number of athletes was small (approximately 270), an effort was made to survey every athlete.

Sampling 100% of any population is difficult. Therefore, an a priori power analysis was performed to establish the ability to determine significance within this study. The survey did not have strong power to detect a 10% difference. However, because this was a pilot study and the N was small, this did not reduce the effectiveness of the results of the study. Contrarily, the power to detect a difference of 30% was high. The study had adequate power to detect a 30% difference because the percent of inadequate knowledge among athletes was expected to be high, therefore only a small sample size was needed to detect a difference.

## Questionnaire Development

The researcher developed a 21-question paper and pencil survey (see Appendix G) based on the Sickle Cell Disease Assessment Survey (Stewart, 2007). Knowledge questions were based upon the online sickle cell education module and quiz developed by Piedmont Health Services and Sickle Cell Agency (Piedmont Health Services and Sickle Cell Agency, 2010).



Many of the questions, for the survey utilized in this study, were modified or self developed because there was not a survey instrument that adequately addressed sickle cell trait as it relates to the athlete and NCAA Guideline 3c. Questions were generated utilizing the research questions which are categorized based on the constructs of the PRECEDE-PROCEED model of program planning for the current study (i.e., social assessment/situational analysis, educational/ecological assessment, etc.). The Health Belief Model and Critical Race Theory were utilized to construct questions as well.

#### *Pilot Testing/Face Validity*

After developing the instrument, it was piloted, for face validity, with an undergraduate community health class. The class consisted of 14 total students: 10 white males, 3 white females, and 1 black male. The students in the class were monitored for time to take the survey, understanding of questions, and ease of survey completion. The first student completed the survey in 2 minutes. The last student took 5 minutes to complete the survey.

Upon questioning, students asked that the box defining “genetic testing” be moved directly above the question for which it related because students often skipped the directions section and went directly to the first question. Therefore, the definition, which related to question 4, was overlooked. This change was made and the definition was placed directly above question 4. A suggestion was also made to separate answers to questions to prevent overlap when circling answers. This change was made. Students reported that they understood each of the questions and did not have any other questions, concerns, or comments regarding the survey.

### *Survey Instrument*

*Questions 1 and 2* were demographic questions that asked for self reported gender and ethnicity. Numbers of surveys for specific teams were pre-determined. The researcher typed in individual names for the teams at the top of the survey. Therefore, the question for sport played was eliminated from the survey because it was no longer needed. *Question 3* asked players to identify tests for which they were tested at the pre-participation physical. Types of tests were listed and players were asked to check “yes”, “no”, or “don’t know” for the responses. They were also asked to check “*I was offered education*” if education was offered for a particular test.

*Questions 4 and 5* asked participants about their likelihood to support voluntary or mandatory testing. Answers were based upon a Likert scale ranging from “*not at all likely*” to “*very likely*”. *Questions 6-11* were SCT knowledge questions. Examples of questions included: “*Sickle cell trait is a disease*” and “*Having sickle cell trait can affect an athlete’s health*”. Each question was accompanied by an answer choice of “*true*”, “*false*”, or “*don’t know*”. “*Don’t know*” was added to minimize guessing and to distinguish those who truly did not know the answer.

*Questions 12-14* determined athletes’ perceived susceptibility and severity of sickle cell trait. Examples of questions included “*I am at risk of having the sickle cell trait*” and “*If I were diagnosed with sickle cell trait, my level of concern would be:*”. *Questions 12-13* were accompanied by Likert scale responses ranging from “*strongly agree*” to “*strongly disagree*”. *Question 14* responses were also based upon a Likert scale and ranged from “*very low*” to “*very high*”.

*Questions 15 and 16* asked about NCAA recommendation 3c knowledge. These questions required a “yes” or “no” response. Question 17 asked participants to determine the degree to which they agreed with an NCAA guideline that recommended voluntary SCT testing, and subsequently in *question 18*, mandatory SCT testing from “very good” to “very bad”. *Question 19* asked participants to determine if genetics testing in general was “very good” to “very bad”. *Questions 20 and 21* were utilized to determine if athletes thought that SCT carriers would be discriminated against. These questions were accompanied by a Likert scale ranging from “strongly agree” to “strongly disagree”.

### *Reliability*

The alpha statistic was run on responses to various questions on the survey to determine internal consistency of the instrument. An alpha of .70 or higher was set as the standard for reliability (Chronbach, 1951). Question 17, “An NCAA guideline that recommends voluntary testing for athletes is...” and question 18, “An NCAA guideline that recommends mandatory sickle cell trait testing for athletes is...” were grouped into the “Perceptions of NCAA testing” scale. The alpha statistic for this scale was .75. Initially question four, “Genetics testing in general is...” was added to the scale. However, it was removed because the addition of this question yielded an alpha statistic of .66 which was lower than the standard of .70. Question 20, “NCAA recommendation 3c might result in athletes with sickle cell trait being treated unfairly, and question 21, “If I were diagnosed with sickle cell trait, I would be given less playing time” were grouped into the “Perception of NCAA discrimination” scale. The alpha statistic for this scale was .58. Knowledge questions were grouped into the “knowledge” subscale. The alpha coefficient for this subscale was .54.

The alpha statistics for the “Perception of NCAA discrimination” and “Knowledge” subscales were lower than .07. This is likely due to the low number of questions for the scales. Also, the questions on the “knowledge” scale asked about varying dimensions of knowledge. Therefore knowledge of how sickle cell disease is inherited was not necessarily related to knowledge of how one is tested for sickle cell trait. The difference in the dimensions of knowledge assessed within the “knowledge” scale likely deflated the Chronbach Alpha coefficients.

### *Validity*

Validity is the accuracy or truthfulness of measurement (Creswell, 2009). There are three types of validity that are commonly discussed in research design. They are face, content, and construct validity. Face validity is the likelihood that a construct will be misunderstood or misinterpreted. To establish face validity, the researcher administered the survey to a class of students at Georgia Southern University. Any questions or misinterpretations that the students had were noted and changed, as described above, before formal administration of the survey.

Content validity refers to whether an instrument adequately covers a topic. To establish content validity, the survey was sent to professors in the College of Public Health at Georgia Southern University and was partially based upon a survey developed by hematologists at Piedmont Health Services and Sickle Cell Agency as well as the Sickle Cell Disease Assessment Survey (Stewart, 2007). A literature review of topics related to sickle cell trait, athletes, and exercise was also performed.

Construct validity refers to the theoretical basis of items on a scale. Construct validity was determined by utilizing the tenets of the Health Belief Model as well as Critical Race Theory

to design questions for the survey. The Health Belief Model was utilized to construct questions related to perception. For example, *question 12* asked participants to rate their perceptions of the statement “*I am at risk of having the sickle cell trait*” along a Likert scale ranging from “*strongly agree*” to “*strongly disagree*”. This question was based upon the perceived risk construct of the Health Belief Model. Question 20 asked participants to rate the statement “*NCAA recommendation 3c might result in athletes with sickle cell trait being treated unfairly*” from “*strongly agree*” to “*strongly disagree*”. This statement was added to the survey to determine if athletes felt that SCT carriers might be discriminated against.

#### Questionnaire Administration

The researcher trained athletic trainers of each team to administer the survey to athletes. The head athletic trainer scheduled a meeting so that all athletic trainers could attend the 30-minute long training. The researcher prepared a PowerPoint that was adapted from the *Men As Navigator for Health Program*, University of North Carolina, Chapel Hill. Training include survey administration protocol (how, when, where to administer survey, informed consent, etc.) and confidentiality. The PowerPoint also included a slide addressing the need to ensure that the athletes voluntarily completed the survey and were not coerced in any way.

Upon completion of training, athletic trainers administered the survey to the athletes. All athletes, of a particular team, met in a central location that was predetermined by the researcher and the team’s athletic trainer as a quiet, comfortable environment that was suitable for survey completion. The athletic trainer read the informed consent form to all athletes. Each athlete was then given a consent form, a survey, and a blank envelope. The consent form was read to the athletes as a group. Upon agreement with the informed consent,

athletes signed the consent form, completed the survey and then placed it in the sealed envelope. Athletic trainers were asked to be sure that athletes did not discuss the survey while they were completing it. If an athlete did not agree to participate, the blank survey and consent form were returned in the sealed envelope. Therefore, there was no way to tell if an athlete did not agree to participate. Each athlete was given a copy of the consent form for his/her records. The athlete returned the survey in a sealed envelope, provided by the researcher, to ensure confidentiality. The athletic trainer then returned all sealed, completed surveys to the envelope provided by the researcher and returned the entire packet to the researcher.

#### Data Analysis

All survey data were entered into the SPSS 18.0 data analysis program utilizing a coding system. *Question 1* asked for participants' gender. Male was coded as 0; Female was coded as 1. *Question 2* asked for participants' self reported race/ethnicity. American Indian or Alaska Native was coded as 0; Asian was coded as 1; Black or African American was coded as 2; Native Hawaiian was coded as 3; White or Caucasian was coded as 4; Hispanic or Latino was coded as 5; Other was coded as 6; and if a participant did not answer, the question was coded as 7. Questions accompanied by a 5- point Likert scale were coded with numbers from 1-5 based on the response. For example, "not at all likely" was coded as 1 and "very likely" was coded as 5. Questions 6-11 were knowledge questions and accompanied by the answer choices "true", "false", or "don't know". They were coded 1, 2, or 3 respectively. Questions 15 and 16 required the participant to answer "yes" or "no". No was coded 0. Yes was coded 1. Questions 17-21 were accompanied by a Likert scale and were coded as stated above.

Data were then recoded into new variables for data analysis. The race variable was recoded into “new race variable”. Black was recoded as 0; white was recoded as 1; and all others were recoded as 2. This was done because the research questions specified differences between Caucasians and African Americans. Therefore, there was a need to exclude all other races from some portions of the analysis. Questions accompanied by a Likert scale were recoded into three groups; disagreement, agreement, and neutral. Responses of 1 or 2 (disagreement) were recoded as 1; Responses of 4 or 5 (agreement) were recoded as 0; Responses of 3 (neutral) remained as 3. Knowledge questions were recoded as a sum of Questions 6-10. This variable, *sumknowledge*, was then recoded based on number of questions answered correctly. The new variable was termed *adequateknowledge*. If the sum of questions answered correctly was from 0-3, then the variable *adequateknowledge* was coded as 0; if the sum of questions answered correctly was from 4-6, then the variable *adequateknowledge* was coded as 1.

After recoding the variables, crosstabs were run on the data. Crosstabs are utilized to determine if there is a correlation between variables. Crosstabulations yielded a p-value. A p-value of less than .05 was determined to be significant. Some of the cells had expected cell counts of less than five. This warranted the need to utilize the p-number generated from the calculation of the Fisher’s Exact coefficient to determine significance. The Fisher’s Exact calculation is only calculated on two-by-two tables. It was necessary that each of the categories, “Agree”, “Neutral”, and “Disagree”, be examined during analysis. This yielded two-by-three or three-by-three tables. Therefore, the Fisher’s Exact test was not run on the data and the initial p-values were utilized for analysis.

## Qualitative Research

Focus groups and in-depth interviews were conducted to answer the research questions as well as to determine themes that emerged.

### *Focus Groups*

A focus group is a common qualitative research method that has been defined as, “A group of individuals selected and assembled by researchers to discuss and comment on, from personal experience, the topic that is the subject of research” (Powell & Single, 1996). Focus groups are a form of group interviews that take advantage of group interactions to generate data (Kitzinger, 1995; Gibbs, 1997). They are highly useful for exploring participant knowledge and experiences and can also be utilized in the examination of how and why people think the way they do (Kitzinger, 1995).

### *Rationale for Use of Focus Group Methodology.*

Researchers have utilized focus groups for various reasons including understanding phenomena and the development of questions for questionnaires or surveys (Hoppe et al, 1995). The purpose of the focus groups in this study was to understand phenomena that relate to the determination of necessary components of an intervention that will be developed to educate intercollegiate athletes, as well as their coaches, about sickle cell trait from pre-participation screening to sickle cell trait diagnosis. The focus group was an integral part of this study because surveys frequently identify gaps between health knowledge and behavior. However only qualitative methods, such as focus groups, can explain these gaps and why they occur (Kitzinger, 1995). Krueger and Casey (2000) states that the focus group is a useful tool when 1) the researcher is looking for a range of ideas or feelings that people have about



something, 2) the researcher is trying to understand differences in perspectives between groups or categories of people, and 3) the purpose is to uncover factors that influence opinions, behavior, or motivation. Each of these was true of the current study.

Focus group methodology was employed in this study because this form of data collection allowed the researcher to gather information concerning participant attitudes, feelings, beliefs, and experiences in ways that are not feasible in other methods (Gibbs, 1997). The group dynamics that resulted from focus groups brought new insight into the topic, taking the research in new, unanticipated directions (Kitzinger, 1995).

#### Data Collection Procedures

##### *The Interview Protocol*

Suggestions by Creswell (2009) were utilized to formulate the basic structure of the interview protocols. They included: the use of a heading, instructions for the interviewer, 4-5 questions with probes, and a final thank you statement to acknowledge the time taken out for the study by the interviewee (p. 183). Suggestions by Krueger and Casey (2000) were utilized to determine the questioning route (p. 44). The following is the suggested questioning route: a) opening questions that are easy to answer, b) introductory questions that introduce the topic, get people thinking, and encourage conversation, c) transition questions that move the conversation into key questions that drive the study, d) key questions that drive the study, and e) ending questions that bring closure to the discussion.

Categories for the questions were based upon the PRECEDE-PROCEED model of program planning (Green & Kreuter, 1999). Therefore, questions were grouped into three of the first four phases of the PRECEDE portion of the model which include: a) Social

Assessment/Situational Analysis, b) Educational/Ecological Assessment, c) Intervention Alignment. No questions were included for phase 2, the epidemiological assessment, because that information was obtained from a review of the literature. An example of the focus group interview guide is included in Appendix H. Below is an explanation of the components of the interview guide.

The initial survey questions were designed to learn about the athletes' sports physicals as well as their daily lives. These questions were grouped based on the social assessment/situational analysis phase of the PRECEDE-PROCEED (PRE-PRO) model of program planning. Question 3 on the quantitative survey asked the athletes to identify items for which they were tested during a pre-participation physical. Athletes were also instructed to place a check into the box labeled "I was offered education" if education was offered on that particular topic. Very few athletes answered this question. Athletes either did not understand the question or did not understand the directions clearly. Therefore, there was a need to ask about the pre-participation screening process in the focus group. Focus group question 1 asked participants what normally happens during a pre-participation health screening/sports physical. This question was asked first because it is something that all athletes are familiar with and can easily relate to. Question 2 asked athletes how they are informed of the results of the screenings. Question 3 was a follow-up to question 2 and asked how participants would like to be informed of the results of the screenings. Therefore question 2 asked for the current procedure and question 3 asked for the athletes' perspectives of the ideal procedure. Question 4 asked what concerns athletes had about coaches or athletic trainers seeing the results of the pre-participation screenings. This question was asked to determine if the athletes had any

reservations about their coaches or athletic trainers obtaining their health information. Various probes such as “what types of things are tested for in a pre-participation health screening” and “Do you know anyone who has had a health issue as a result of pre-participation screening” were added to this section to gain a better understanding of athletes experiences with pre-participation screening.

The subsequent section was grouped into the ecological/educational assessment. Questions 6-11 of the quantitative survey asked athletes questions about sickle cell. Sixty-nine percent of the 259 survey respondents answered the question “Sickle cell is a disease” incorrectly. Seventy-six (76.1%) percent of participants were found to have adequate knowledge of sickle cell disease based on the quantitative survey results. However, it was difficult to determine if this was a result of guessing or of true knowledge. Therefore, question 5 of the focus group asked athletes, “What do you know about sickle cell trait?”. This question was accompanied by probes that delved further into the knowledge base of participants. Question 6 asked participants about knowledge of NCAA recommendation 3c. This question was placed on the survey to compliment questions 15-16 of the survey which asked about awareness concerning NCAA recommendation 3c. Question 7 of the focus group asked participants about their feelings about voluntary and mandatory SCT testing. These questions corresponded to questions 17-19 on the survey that asked participants to rate their feelings concerning genetics testing on a Likert scale from “very good.....very bad”. Question 8 asked participants about how they would feel if found to have SCT during a pre-participation health screening. Question 9-12 were designed to determine if athletes had any perceived racism whether in athletics or on campus. It was necessary to determine perceived racism because of

the critical approach to the study. However, it was also important that athletes not be coerced into stating that they perceived racism. Therefore, questions 9-12 were phrased carefully.

Question 9 asked participants if they believed that NCAA recommendation 3c would have more of an effect on some athletes than others. Question 10 asked athletes if there were any differences in how Caucasian and African American athletes were treated on campus. Question 11 explained the controversy concerning the NCAA recommendation and asked if athletes had any experiences with racism within college athletics. Question 12 asked athletes to identify long term consequences, good or bad, of NCAA 3c.

Questions 13-16 were grouped into the intervention alignment and administrative and policy assessment phase of the PRE-PRO model. These questions could not be asked in the quantitative survey. Therefore it was necessary to determine the daily rituals of the athletes during the focus groups. Question 13 asked participants to describe a typical day in their lives. Question 14 asked participants specifically how they would like for an education session to look. Question 15 asked participants from whom they would like to receive health education. Question 16 asked participants about ways to improve upon the pre-participation physical process. Probes were utilized in this section as well to further determine the daily activities of the athlete. The final question asked athletes to discuss any additional information they may have had for the researcher.

### *Sampling of Participants*

Qualitative research typically focuses on small, purposefully selected samples to drive inquiry and develop understanding. In purposeful samples, cases are selected because they are information rich. This allows for insight rather than generalizations (Patton, 2002). The

participants in the qualitative portion of the study were a subset of individuals who had taken the quantitative survey. A form was given to the head athletic trainer and strength and conditioning coach that listed the desired ethnicity, gender, and sport played for each participant in the focus group. If an athlete matched the specifications, they were placed into the focus group. For example one of the spaces on the sign-up sheet read: "African American/Male/Football". Therefore, if an African American male football player volunteered, he was placed into that particular slot. This was pre-determined based upon the fact that the majority of African American athletes at Georgia Southern University play football, basketball, or run track. These are also the sports where deaths have occurred as a result of SCT. Therefore, there was a need to over sample individuals from these sports. Also, there was an effort made to have equal numbers of males and females in each of the groups; although this did not always happen.

Focus group participants were self-selected male and female athletes between the ages of 18-24 who participated in an intercollegiate athletic team at Georgia Southern University. Participants self-identified as African American or Caucasian. Participants were divided into 3 focus groups. The first group was a Caucasian-only group. The second group was an African American-only group. The third group was a mixture of African American and Caucasian athletes selected from participants in the first two groups.

#### *Recruitment of Participants*

The researcher contacted the head athletic trainer who was already familiar with the study because of participation in the quantitative data collection phase of the study. The head athletic trainer then contacted the strength and conditioning coach to explain the study. This

coach had frequent contact with the players and was determined to be the best contact for recruitment of players. The strength and conditioning coach was then contacted by the researcher via email to schedule a face-to-face meeting to explain the research study. The researcher and strength and conditioning coach then scheduled a time for the researcher to come and talk to the athletes concerning the study. This was during a time when all athletes were required to be in the weight room for lifting. After the researcher explained the study to the athletes, they were asked to write their names and contact information on a sheet provided by the researcher if they wished to participate. The initial proposal of the study called for six focus groups: two Caucasian, two African American, and two mixed ethnicity groups. Because the data collection period was during the summer, many athletes were unavailable or unwilling to participate. Therefore, a total of 20 names with corresponding emails and phone numbers were collected. Three focus groups were conducted. The researcher contacted the individuals who expressed a desire to participate in the study via email and text messages. Each individual who signed up for the focus groups agreed to participate when contacted. Individuals were placed into one of 2 focus groups, by the researcher, strategically based on self-identified ethnicity.

### Setting

The focus groups took place at Georgia Southern University in a room that was quiet, comfortable, and familiar to participants as is suggested in Creswell (2009). This place was identified as Kennedy Hall by the athletic director and head athletic trainer. This is the dorm where athletes live and have study hall. It is against policy at Georgia Southern University to

incentivize athletes. Therefore, athletes did receive compensation. However, pizza and cokes were served at each focus group.

#### Informed Consent

The researcher went through the informed consent process with the participants prior to initiation of the focus groups. The form consisted of information about the study, termination of participation in the study, risks/benefits of the study, as well as contact information for the researcher and the IRB at Georgia Southern University. Participants were informed that the session was recorded, but would be utilized for research purposes only. Upon agreement, each participant signed the IRB form and was given a copy of the form for his/her records.

#### Focus Group Design

The design of the focus groups in this study was a multiple-category design. This design allowed the researcher to make comparisons in two ways-from one group to another within a category and from one category to another category (Krueger & Casey, 2000). The design was as follows (O=1 group):

Audience 1:	Caucasian athletes	O
Audience 2:	African American Athletes	O
Audience 3:	Caucasian/African American Athletes	O

#### In-Depth Interviews

The in-depth interview is a method of face-to-face interviewing with an individual. Its purpose is to gain insight into a person's beliefs and perspectives on an issue. The individual being interviewed is seen as the expert whereas the individual who is interviewing is seen as

the student (Family Health International, 2010). In this study, it was important to gain the individual perspectives of the coaches, athletic trainers, and hematologists. The information gained from each of these perspectives required more detail and in-depth questioning than would be allowed in a group setting like a focus group. Also, it was difficult to coordinate the schedules of each of these individuals. Therefore, the in-depth interview was scheduled at a time and place that is convenient for each individual. Some of the interviews were conducted via the telephone.

### *Participants*

Four coaches, one athletic trainer, and one hematologist took part in in-depth interviews. The hematologist was interviewed to gain the perspective of a medical professional about information that should be included in a program designed to educate coaches and athletes about SCT.

### *Recruitment of Participants*

Each coach and athletic trainer was contacted first via email concerning the study and the desire for the interview. Then, the researcher contacted the athletic marketing director to assist in recruitment of the coaches. The athletic marketing director then contacted each of the coaches and assisted with scheduling the interviews. The hematologist was called and a telephone interview time was scheduled. The hematologist was a hematologist/oncologist who specializes in sickle cell disease/trait.

### **Data Collection**

The researcher conducted each in-depth interview to maintain consistency in data collection and analysis. All interviews were audio recorded and brief notes were taken. The



audio recording and notes were transcribed verbatim by an outside transcriptionist and then reviewed for errors and corrected by the researcher.

### Data Analysis

All data was read and digital recordings were listened to by the researcher within 24 hours after the focus group. Within 48 hours of the focus group, the researcher debriefed with the note taker, when applicable. Data from the in-depth notes and digital recordings were transcribed verbatim by an outside transcriptionist. Transcripts were reviewed while listening to the recording and mistakes were corrected by the researcher.

An a priori code book was developed while the data was being transcribed. A priori codes were based upon constructs from the Health Belief Model, Critical Race Theory, and preliminary findings from initial review of the focus groups and interviews. Examples of codes were “DAY RIT” which was defined as “daily rituals of the athletes”; “A KNOW SCT” which was defined as “Athlete knowledge of Sickle Cell Trait”; “PER RAC” which was defined as perceived racism; and “INT CON” which was defined as interest convergence (see Appendix K).

One transcript and the a priori code list were sent to two outside researchers for review. This allowed the researcher to discuss the data with unbiased researchers and enhanced the dependability of the study. It was suggested that some codes be expanded. These corrections were made. New codes, such as “POS HLTH SH”, which was defined as “Positives of health information sharing, and “A PER PHYS”, which was defined as “Athlete’s perceptions of sports physicals”, were added to the code book.

Transcript data as well as codes were then uploaded into version 6.0 of Atlas.ti, a commonly used qualitative data analysis software (Atlas.ti®, 2010). Codes were grouped into

organizational categories, called “families” in Atlas.ti, that were named based upon the first 4 phases of the PRECEDE-PROCEED planning model. Output was then grouped into the PRECEDE-PROCEED categories. This allowed the researcher to read all participant comments that corresponded to the PRECEDE-PROCEED assessment and subsequently recognize themes that emerged. All data was read several times so that the overall theme of the data was not overlooked because of the adherence to PRECEDE-PROCEED categories. Qualitative data collection was an iterative process. Data were read and memos were written and re read until common themes emerged. All data was kept, by the researcher in a secure file cabinet, and was accessible only to the researcher.

### Trustworthiness

Lincoln and Guba (1985) define four criteria for evaluating a qualitative study. These are credibility, transferability, dependability, and confirmability. Collectively, these provide a framework to determine the trustworthiness of a study.

#### *Credibility*

Credibility is the assurance that the findings from a qualitative inquiry are true. Methods utilized in the current study to enhance credibility are triangulation, peer debriefing, negative case analysis, and member checking. Each of these is defined and explained in the context of the study below.

#### *Triangulation.*

Triangulation involves the use of multiple data sources within an inquiry to produce understanding (Patton, 2002). Three types of triangulation (methods triangulation, analyst triangulation, and theory perspective triangulation), as described by Patton (2002) were utilized

in this study. *Methods triangulation* is determining the consistency of findings by utilizing mixed methods. The study is designed as a mixed methods study. Therefore quantitative and qualitative methods are collected, analyzed, and compared for consistency. *Analyst triangulation* is using multiple analysts to review findings. The researcher and two doctoral level qualitative researchers reviewed, discussed, and analyzed the qualitative data. *Theory/perspective triangulation* is utilizing multiple perspectives or theories to interpret data. Critical Race Theory and the Health Belief Model were utilized as the theoretical foundation for this study. Each was utilized to guide the analysis of data in both the quantitative and qualitative portions of the study.

#### *Peer Debriefing.*

Peer debriefing "is a process of exposing oneself to a disinterested peer in a manner paralleling an analytic session and for the purpose of exploring aspects of the inquiry that might otherwise remain only implicit within the inquirer's mind" (Lincoln & Guba, 1985, p. 308). Lincoln & Guba (1985) define 4 purposes of peer debriefing: a) to help uncover taken for granted biases, perspectives and assumptions on the researcher's part, b) to allow the researcher to become aware of his/her posture toward data and analysis, c) to provide an opportunity to test and defend emergent hypotheses and see if they seem reasonable and plausible to a disinterested debriefer, and d) to provide the researcher with an opportunity for catharsis (discharge of emotion). In the current study, two doctoral level researchers were utilized as peer debriefers. Each coded a section of data for the researcher and then discussed the codes as well as themes that emerged. This allowed the researcher to think through the findings and to determine the best way to convey the data.

### *Negative Case Analysis.*

Negative case analysis involves seeking out and illuminating elements of the data that are contradictory (Patton, 2002). This allows for greater refinement of an analysis and allows the researcher to broaden and confirm emergent themes (Lincoln & Guba, 1985). In the current study, there were cases that were contrary to the emergent themes. These cases were highlighted and discussed within the context of the theme they contradicted.

### *Member Checking.*

Lincoln & Guba (1985) states that member checking is the most crucial technique for establishing credibility. Member checking is when data, analytic categories, interpretations and conclusions are tested with the originators of the data (Cohen & Crabtree, 2006). This technique allows the researcher to verify the accuracy of an account. The design of the current study contributed to member checking. Focus group 3 was a combination of individuals from focus groups 1 and 2. This allowed the researcher to review transcripts from focus group 1 and 2 to determine information that needed to be clarified during focus group 3. Participants were asked about general concepts from the previous groups to determine accuracy of researcher interpretation.

### *Thick Description*

Thick description is the second criteria for credibility as outlined by Lincoln & Guba (1985). Thick description is a way of achieving the qualitative equivalent to external validity. By describing an account with ample detail, the researcher can evaluate the extent to which the conclusions drawn are transferable to other times, settings, situations, and people (Cohen & Crabtree, 2006). Detailed notes were taken about the participants and

settings of the focus groups and in-depth interviews. Each of these is described in detail in this study. An analysis of the implications of the location of the study is also explained in chapter three.

### *Dependability*

Dependability is established by utilizing an external auditor. An external auditor is one who is not involved in the research process. This individual examines the research processes as well as products (Cohen & Crabtree, 2006). This process allows the researcher to improve the accuracy and validity of the study. The very nature of doctoral research inquiry requires that the research is consistently reviewed by external auditors. The research procedures and findings of the study have been reviewed and refined through an iterative process.

### *Confirmability*

Confirmability is “the degree of neutrality or the extent to which the findings of a study are shaped by the respondents and not researcher bias, motivation, or interest (Cohen & Crabtree, 2006). Lincoln & Guba (1985) lists 4 strategies for establishing confirmability: 1) confirmability audit, 2) audit trail, 3) triangulation, and 4) reflexivity. The confirmability audit and triangulation have been discussed in the context of this study. Therefore the audit trail and reflexivity will be explained further in this section.

#### *Audit Trail.*

An audit trail is a detailed account of every process of a research study from initiation to completion. In this study written field notes, data summaries, notes containing structure of categories (themes, definitions, and relationships) and instrument development information,

including pilot data, schedules, and participant questionnaires were all collected and stored by the researcher throughout the research process.

#### *Reflexivity.*

“Reflexivity is an attitude of attending systematically to the context of knowledge construction, especially to the effect of the researcher, at every step of the research process” (Cohen & Crabtree, 2006). This step in determining trustworthiness of this research has been one of the most pertinent. The researcher’s personal experience with sickle cell anemia brought about undeniable experiences with discrimination and therefore bias within the context of the research. The researcher consistently reflected upon these biases by journaling and debriefing with outside researchers. The researcher has been open and honest about these biases within the data analysis and reporting of the research findings. The research has been thoroughly reviewed by and discussed with outside researchers in order to reduce bias. Data that was discrepant to the hypotheses of the researcher were explained and illuminated throughout this research.

#### *Assumptions.*

This study is based upon the following assumptions. 1) Participants answered the questions honestly. 2) Athletes were not coached regarding how to answer before taking the survey or participating in the focus groups. 3) The instrument was valid and measured the constructs that it was designed to measure.

### Chapter Summary

The purpose of this chapter was to outline the mixed methods design of the study. Phase I utilized a 21-question survey to determine the attitudes and perceptions of 259

athletes. Phase II consisted of three focus groups; one white, one African American, and one mixed ethnicity, as well as in-depth interviews of four coaches, one athletic trainer and one hematologist. The next chapter describes the results of data collection in phase I.

Subsequently, chapter 5 will describe the themes that emerged from qualitative data collection.

## CHAPTER 4

### PHASE I: QUANTITATIVE ANALYSIS FINDINGS

#### Introduction

The purpose of chapters four and five is to summarize the quantitative and qualitative data collected and analyzed in order to answer the study's research questions. In order to best highlight the findings from each phase of the study, the chapters are divided into two sections, quantitative and qualitative.

#### Phase I: Quantitative Analysis Results

##### *Sample Characteristics*

A total of two-hundred seventy (270) questionnaires were distributed to college athletes across 13 sports during the month of April 2010. Eleven questionnaires were not completed because surveys consisted of numbers counted for players who were absent at the time of data collection. This resulted in a total sample size of 259; resulting in a response rate of 96.0%. Table 7 provides an overview of the descriptive characteristics of the participants. There were (61.0%; n=158) male athletes and 101 female (39.0%) athletes. Seventy-two athletes (27.8%) self-identified as Black/African American. One (0.4%) athlete self-identified as Native Hawaiian/Other Pacific Islander. One hundred seventy-six (68.0%) of the athletes who participated in the study self-identified as White/Caucasian. Five (1.9%) athletes self-identified as Hispanic/Latino. Five athletes (1.9%) self-identified as Other.

There are 13 NCAA regulated sports played at Georgia Southern University. Athletes representing each sport participated in the study. There were: 1) 28 men's baseball, 2) 7 men's golf, 3) 13 women's swimming and diving team, 4) 27 women's track and field, 5) 89 football, 6)



11 women's soccer, 7) 17 men's soccer, 8) 11 women's volleyball, 9) 10 women's basketball, 10) 6 men's basketball, 11) 10 women's tennis, 12) 11 men's tennis, and 13) 19 softball. A description of the demographic variables is displayed in Table 7.

### *Results of Quantitative Analysis*

The following are the results of the quantitative analysis. They are also illustrated in Table 8. The results are reported according to research question and associated hypotheses. The knowledge questions were re coded and grouped into "adequate" and "inadequate knowledge". Adequate sickle cell knowledge was based upon participants answering four or more of the six knowledge questions correctly. Adequate knowledge of NCAA 3c was based upon answering "yes" to the question, "*Are you aware that there is an NCAA guideline that is specific to sickle cell trait and the athlete?*" The answer choices to the remaining questions were based upon a 5-point Likert Scale and were accompanied by one of the following sets of answer choices: a) "Strongly Agree" to "Strongly Disagree", or b) "Very Good to Very Bad". Answers were re coded and placed into 3 groups: a) "Strongly Agree/Agree", "Neutral", and "Strongly Disagree/Disagree", or "Very Good/Good", "Neutral", and "Very Bad/Bad". The groups were re coded for ease of data analysis. It was not necessary to distinguish whether or not an individual agreed or strongly agreed. Therefore agreement and disagreement statements were grouped together.

Research question 3 was, "*Do the predisposing, enabling, and reinforcing factors that influence athletes' outlooks on SCT and NCAA differ among ethnic groups?*" This question had 6 hypotheses that were designed to determine if there were differences among ethnic groups. "Ethnic groups" was defined as Caucasian or African American. The "Race" variable was re

coded into a “White and Black Only” variable. Those who self identified as Native Hawaiian/Other Pacific Islander (N=1), Hispanic/Latino (N=5), or Other (N=5) were excluded from analysis. Black/African American was re coded as 0. White/Caucasian was re coded as 1. All other race/ethnicities were re coded as “Other”. “Other” was re coded as 3. For analysis, cases that were not recoded as 0 or 1 were excluded (n=11). This changed the N for analysis of question 3 to 248. This decision was made during the design of the study because one of the purposes of the study was to determine differences in knowledge, perceptions, etc. among white and black athletes. Therefore, it was necessary to remove those who self-identified as any other race/ethnicity. The following are the results of data analysis outlined by research question. Table 5 illustrates the research questions and their associated hypotheses.

#### Research Question 1

What are the predisposing, enabling, and reinforcing factors that influence athletes’ outlook on SCT Testing?

There were three hypotheses associated with research question 1:

- 1) Knowledge of SCT is not associated with athlete outlook on SCT testing.
- 2) Perceived risk of having SCT is not associated with athlete outlook on SCT testing
- 3) Perceived importance of knowing s/he has SCT is not associated with athlete outlook on SCT testing.

To answer this question, first, demographic frequencies for adequate sickle cell knowledge, as well as questions 12 (I am at risk of having the sickle cell trait), 13 (It is important for an athlete to know if s/he has the sickle cell trait), 17 (An NCAA guideline that recommends voluntary sickle cell trait testing for athletes is...), and 18 (An NCAA guideline that recommends

mandatory sickle cell trait testing for athletes is...) were calculated utilizing SPSS 18 Statistical Data Analysis Package. A rationale for the use of these questions is included in the explanation of the descriptive frequencies below.

#### *Adequate Sickle Cell Knowledge*

A majority (76.1%) of the athletes had adequate sickle cell knowledge. About one-fourth (23.9%; n=62) of athletes answered less than four questions correctly indicating inadequate knowledge of SCT.

#### *Perception of Risk of SCT*

Question 12 asked participants to indicate their perception of risk of having SCT. Athletes perceptions of risk were as follows: a) 60.2% did not perceive that they were at risk for having SCT, b) 13.5% believed that they were at risk for having SCT; and c) 26.3% indicated that they were neutral.

#### *Perception of Importance of Knowing if S/he has SCT*

Question 13 asked participants to indicate their perception of the importance of an athlete knowing whether or not s/he has SCT. Athlete perceptions were as follows: a) 89.6% (n=232) indicated that it was important for an athlete to know if he/she has SCT, b) 1.9% (n=5) disagreed athletes should know their SCT status, and c) 8.5% (n=22) responded "neutral".

#### *Voluntary SCT Testing by the NCAA*

Question 17 asked participants about their perceptions of an NCAA guideline that called for voluntary SCT testing for athletes. Athlete perceptions were as follows: a) 68.7% (n=178) believed that an NCAA Guideline that called for voluntary SCT testing for athletes was "Very

Good/Good”, b) 13.5% (n=15) believed that an NCAA guideline that called for voluntary SCT testing was “Very Bad/Bad”, and c) 26.3% (n=66) responded “Neutral”.

#### *Mandatory SCT Testing by the NCAA*

Question 18 asked participants about their perceptions of an NCAA guideline that called for mandatory SCT testing for athletes. Athlete perceptions were as follows: a) 72.2% (n=187) believed that an NCAA Guideline that called for mandatory SCT testing was “Very Good/Good”, b) 2.7% (n=7) responded “Very Bad/Bad”, and c) 25.1% (n=65) responded “Neutral”. Table 8 illustrates the descriptive frequencies for adequate sickle cell knowledge, as well as questions 12, 13, 17, and 18.

Subsequent to the calculation of descriptive frequencies for adequate knowledge and questions 12, 13, 17, and 18, cross tabulations were run on the data. Adequate knowledge as well as questions 12 and 13 was cross tabulated with questions 17 and 18. The rationale for this analysis was that cross tabulations determine associations between independent and dependent variables. Therefore, since the hypotheses called for the determination of associations, this calculation was appropriate for analysis.

The rationale for the use of questions 17 and 18 was that they were the questions specific to SCT testing. Question 17 asked participants to rate their perceptions, from “Very Good” to “Very Bad”, of an NCAA guideline that recommended voluntary SCT testing. Question 18 asked participants to rate their perceptions, from “Very Good” to “Very Bad”, of an NCAA guideline that recommended mandatory SCT testing.

### *Hypotheses 1 and 7*

*Knowledge of SCT is not associated with athletes' outlooks on SCT testing.*

*Knowledge of SCT will not differ significantly among ethnic groups.*

A chi-square analysis was conducted to test the null hypothesis that knowledge of SCT is not associated with athletes' outlooks on SCT testing. Knowledge was cross tabulated with question 17 (voluntary SCT testing). There were no significant differences ( $p = .117$ ) between those with adequate knowledge of SCT and those with inadequate knowledge of SCT in attitudes towards voluntary SCT testing. Therefore the study failed to reject the null hypothesis that knowledge of SCT is not associated with athletes' outlooks on SCT testing.

Of those with adequate SCT knowledge: a) 54.4% ( $n=141$ ) responded that an NCAA guideline that recommends voluntary SCT testing was "Very Good/Good", b) 4.6% ( $n=12$ ) responded "Very Bad/Bad", and c) 17.0% ( $n=44$ ) were "Neutral". Athletes with inadequate SCT knowledge responded: "Very Good/Good" (14.3%), "Very Bad/Bad" (1.2%), "Neutral" (8.5%).

There were significant differences ( $p=.015$ ) between those with adequate knowledge of SCT and those with inadequate knowledge of SCT in attitudes towards mandatory SCT testing. The odds ratio was 1.68. Therefore those with adequate SCT knowledge were 68% more likely to say that mandatory SCT testing under an NCAA guideline was very good/good than those with inadequate knowledge. Therefore the null hypothesis was rejected.

Those with adequate SCT knowledge responded that an NCAA Guideline that recommends mandatory SCT testing was "Very Good/Good" (58.3%), "Very Bad/Bad" (1.9%), and "Neutral" (15.8%) respectively. Athletes with inadequate SCT knowledge responded "Very Good/Good" (13.9%), "Very Bad/Bad" (0.8%), and Neutral (9.3%) respectively.

There were no significant differences ( $p=.518$ ) in SCT knowledge between black and white athletes. Therefore the study failed to reject the null hypothesis that that knowledge of SCT will differ significantly among ethnic groups. Of those with inadequate knowledge (25%), 8.1% were African American and 16.9% were Caucasian. Of those with adequate knowledge (75%), 21.0% were African American and 54.0% were Caucasian. The results of the cross tabulations of adequate SCT knowledge and attitude towards voluntary NCAA SCT testing, mandatory SCT testing and race/ethnicity are illustrated in Table 9.

#### *Hypotheses 2 and 8*

*Perceived risk of SCT is not associated with athletes' outlooks on SCT testing.*

*Perceived risk of having SCT will differ significantly among ethnic groups.*

There were no significant differences ( $p=.126$ ) between those who agreed that they were at risk for having SCT and those who did not believe that they were at risk of having SCT. Therefore, the study failed to reject the null hypothesis that perceived risk of SCT is not associated with athletes' outlooks on SCT testing.

Those who agreed that they were at risk for SCT (13.5%), responded that an NCAA guideline that recommended voluntary SCT testing was "Very Bad/Bad" (0.8%), "Very Good/Good" (10.0%), and "Neutral" (2.7%) respectively. Those who did not believe they were at risk for having the SCT (60.2%), responded "Very Good/Good" (42.1%), "Very Bad/Bad" (4.6%), and Neutral (13.5%) respectively. Those who were "Neutral" (26.3%) responded "Very Good/Good" (16.6%), "Very Bad/Bad" (0.4%), and Neutral (9.3%) respectively.

There were no significant differences ( $p=.411$ ) between those who agreed that they were at risk for having SCT and those who did not believe that they were at risk of having SCT in

outlook on mandatory SCT testing. Therefore the study failed to reject the null hypothesis that perceived risk of having SCT is not associated with athletes' outlooks on SCT testing.

Those who agreed that they were at risk for SCT, responded that an NCAA guideline that recommended mandatory SCT testing was "Very Bad/Bad" (0.0%), "Very Good/Good" (10.8%), and "Neutral" (2.7%) respectively. Athletes who did not believe they were at risk for having the SCT, responses were "Very Good/Good" (43.6%), "Very Bad/Bad" (2.3%), and "Neutral" (14.3%) respectively. Those who were "Neutral" responded "Very Good/Good" (17.8%), "Very Bad/Bad" (0.4%), and "Neutral" (8.1%) respectively.

There were significant differences ( $p=.000$ ) in perceptions of risk of SCT between ethnic groups. The odds ratio was 9.2. Therefore, Caucasians were 9.2 times more likely than African Americans to strongly disagree that they were at risk of having SCT. The study rejected the null hypothesis that perceived risk of having SCT will not differ significantly among ethnic groups.

Of those who "Strongly Disagreed/Disagreed" (60.5%) with the statement, "*I am at risk of having sickle cell trait*", 12.1% were African American and 48.4% were Caucasian. Of the athletes who "Strongly Agreed/Agreed" (13.3%), 9.3% were African American and 4.0% were Caucasian. Of those who were "Neutral" (26.2%), 7.7% were African American and 18.5% were Caucasian (See Table 10).

*Hypotheses 3 and 9*

*Perceived Importance of knowing he/she has SCT is not associated with athletes' outlooks on SCT testing.*

*Perceived importance of knowing he/she has SCT will not differ among ethnic groups.*

There were significant differences ( $p < .000$ ) between those who agreed that it was important for athletes to know if they have SCT and those who do not believe it is important for athletes to know if they have SCT in attitudes towards an NCAA guideline that recommended voluntary SCT testing. Therefore, the null hypothesis that perceived importance of knowing he/she has SCT is not associated with athletes' outlook on SCT testing was rejected.

Those who agreed that it was important for an athlete to know if he/she has the sickle cell trait, responded that an NCAA guideline that recommended voluntary SCT testing was "Very Bad/Bad" (5.8%), "Good/Very Good" (65.3%), "Neutral" (18.5%) respectively. Those who did not agree that it was important for an athlete to know he/she has sickle cell trait responded "Very Bad/Bad" (0.0%), "Very Good/Good" (0.4%), and "Neutral" (1.5%) respectively. Those who responded, "Neutral" to the question of whether or not it is important for athletes to know their SCT status, responded "Very Bad/Bad" (0.0%), "Very Good/Good" (3.1%), and "Neutral" (5.4%) respectively concerning voluntary SCT testing.

There were significant differences ( $p < .001$ ) between those who agreed that it was important for athletes to know if they have SCT and those who did not believe it is important for athletes to know if they have SCT in attitudes towards an NCAA guideline that recommended mandatory SCT testing. Therefore, the null hypothesis that perceived



importance of an athlete knowing if s/he has the sickle cell trait was not associated with athletes' outlook on sickle cell trait testing was rejected.

Those who agreed that it was important for an athlete to know if s/he has the sickle cell trait, responded that an NCAA guideline that recommended mandatory SCT testing was "Very Bad/Bad" (1.5%), "Very Good/Good" (68.0%), and "Neutral" (20.1%). The athletes who did not believe it was important for an athlete to know if s/he has the sickle cell trait, responded "Very Good/Good" (1.5%), "Very Bad/Bad" (0.0%), and "Neutral" (0.4%) respectively. The athletes who responded, "Neutral" to the question of whether or not it is important for athletes to know their SCT status, responded "Very Bad/Bad" (1.2%), "Very Good/Good" (2.7%), and "Neutral" (4.6%) respectively concerning mandatory SCT testing.

There were no significant differences ( $p=.205$ ) in perceived importance of knowing he/she has SCT between ethnic groups. Therefore the study failed to reject the null hypothesis that perceived importance of knowing he/she has SCT will differ significantly among ethnic groups. Of those who, "Strongly Disagreed/Disagreed" (1.6%), 0.0% were African American and 1.6% were Caucasian. Of those who "Strongly Agreed/Agreed" (89.6%), 27.4 % were African American and 62.1 % were Caucasian. Of those who responded "Neutral" (8.9%), 1.6% were African American and 7.3% were Caucasian. Table 10 illustrates the association between perceived importance of an athlete knowing if he/she has SCT and voluntary/mandatory SCT testing and race/ethnicity.

## Research Question 2

*What are the predisposing, enabling, and reinforcing factors that influence athletes' outlook on NCAA Guideline 3c?*

There were 3 hypotheses associated with research question 2:

Hypothesis 4: Knowledge of NCAA 3c is not associated with athlete outlook on NCAA 3c.

Hypothesis 5: Perception that NCAA 3c might result in athletes with SCT being treated unfairly is not associated with athlete outlook on NCAA 3c

Hypothesis 6: Athletes' perceptions of receiving less playing time if he/she was diagnosed with SCT is not associated with outlook on NCAA 3c.

To answer this question, first, demographic frequencies for NCAA 3c knowledge, as well as questions 15, 17, 18, 20, and 21 were calculated utilizing SPSS 18 Statistical Data Analysis Package. A rationale for the use of these questions is included in the explanation of the descriptive frequencies below.

### *NCAA3c Knowledge*

A majority of the athletes (n=146; 56.4%) were not aware of NCAA Guideline 3c: Sickle Cell Trait and the Athlete. Knowledge of NCAA 3c was based upon participants answering "yes" or "no" to question 15; "Are you aware that there is an NCAA Guideline that is specific to sickle cell trait and the athlete?" Approximately 43.2% (n=112) of athletes indicated that they were aware of NCAA Guideline 3c.

### *NCAA 3c and Unfair Treatment*

Question 20 asked participants to indicate their perception of whether or not NCAA 3c might result in athletes being treated unfairly. Question 20 read, "NCAA recommendation 3c

*might result in athletes with SCT being treated unfairly*". In this sample, 34% (n=88) of athletes did not perceive that athletes with SCT would be treated unfairly; 13.5% (n=35) of athletes believed that athletes would be treated unfairly; and 52.5% (n=136) of athletes indicated that they were neutral in response to their perception of athletes with SCT being treated unfairly as a result of NCAA 3c.

#### *Athletes' Perceptions of Having Less Playing Time if S/He has SCT.*

Question 21 asked participants to indicate their perception of receiving less playing time if diagnosed with SCT. Question 21 read, *"If I were diagnosed with SCT, I would be given less playing time"*. Thirty-seven percent (37.1%; N=96) of athletes indicated that they did not believe they would receive less playing time if diagnosed with SCT. A small number of athletes (N=27; 10.4%) believed they would have less playing time if diagnosed with SCT. The majority of athletes (N=136; 52.5%) were neutral concerning their perceptions of receiving less playing time if diagnosed with SCT.

#### *Voluntary Genetics Testing by the NCAA*

Question 17 asked participants about their perceptions of an NCAA guideline that called for voluntary SCT testing for athletes. A majority of the athletes (68.7%, n=178) believed that an NCAA Guideline that called for voluntary SCT testing for athletes was "Very Good/Good". The proportion of athletes believing that an NCAA guideline that called for voluntary SCT testing was "Very Bad/Bad" was 5.8% (n=15). The remaining 25.5% (n=66) of athletes responded "Neutral".

### *Mandatory Genetics Testing by the NCAA*

Question 18 asked participants about their perceptions of an NCAA guideline that called for mandatory SCT testing for athletes. A majority of the athletes (n=187; 72.2%) believed that an NCAA Guideline that called for mandatory SCT testing for athletes was “Very Good/Good”. The proportion of athletes believing that an NCAA guideline that called for mandatory SCT testing was “Very Bad/Bad” was 2.7% (n=7). The remaining 25.1 % (n=65) of athletes responded “Neutral” to this question. Table 12 illustrates the descriptive frequencies for NCAA 3c knowledge, as well as questions 17, 18, 20, and 21.

Subsequent to the calculation of descriptive frequencies for NCAA knowledge and questions 17, 18, 20, and 21, cross tabulations were run on the data. NCAA 3c knowledge as well as questions 20 and 21 were cross tabulated with questions 17 and 18. The rationale for the use of questions 17 and 18 was that they were the questions specific to NCAA Guideline 3c and SCT testing.

### *Hypotheses 4 and 10*

*Knowledge of NCAA 3c is not associated with athletes’ outlooks on NCAA 3c.*

*Knowledge of NCAA 3c will not differ significantly among ethnic groups.*

There were no significant differences ( $p=.169$ ) between those who had knowledge of NCAA 3c and those who did not in attitudes towards voluntary SCT testing. Therefore, the study failed to reject the null hypothesis that knowledge of NCAA 3c is not associated with athletes’ outlooks on NCAA 3c.

Those with knowledge of NCAA 3c, responded that an NCAA Guideline that recommends voluntary SCT testing was “Very Good/Good” (30.9%). “Very Bad/Bad” (3.5%),

and “Neutral”(8.9%) respectively. Athletes with no knowledge of NCAA 3c, responded “Very Good/Good” (37.8%), “Very Bad/Bad”( 2.3%), and “Neutral” (16.2%) respectively.

There were no significant differences ( $p=.152$ ) between those with knowledge of NCAA 3c and those with no knowledge of NCAA 3c in attitudes towards mandatory SCT testing. Those with knowledge of NCAA 3c, responded that an NCAA Guideline that recommends mandatory SCT testing was “Very Good/Good” (34.0%), “Very Bad/Bad” (0.8%), and “Neutral” (8.5%) respectively. Those with no knowledge of NCAA 3c responded “Very Good/Good” (38.2%), “Very Bad/Bad” (1.9%), and “Neutral” (16.2%) respectively.

There were no significant differences ( $p=.737$ ) in NCAA knowledge between black and white athletes. Therefore, the study failed to reject the null hypothesis that that knowledge of NCAA 3c will not differ significantly among ethnic groups. Of those who had knowledge of NCAA 3c (43.1%), 12.1% were African American and 31.0% were Caucasian. Of those who did not have knowledge of NCAA 3c, 16.9% were African American and 39.5% were Caucasian. Table 13 illustrates the association between knowledge of NCAA 3c and attitude towards voluntary/mandatory NCAA SCT testing and race/ethnicity.

#### *Hypotheses 5 and 11*

*Perception that NCAA 3c might result in athletes with SCT being treated unfairly is not associated with athletes’ outlooks on NCAA 3c.*

*Perception that NCAA 3c might result in athletes with SCT being treated unfairly will not differ significantly among ethnic groups.*

There were significant differences ( $p=.038$ ) between those who agreed that NCAA 3c might result in unfair treatment and those who did not agree that NCAA 3c might result in

unfair treatment. The odds ratio was 1.75. Therefore, those who strongly disagree/disagree that athletes will be treated unfairly are 75% more likely to think that a voluntary SCT test is good. The study rejected the null hypothesis that perception that NCAA 3c might result in athletes with SCT being treated unfairly is not associated with athletes' outlooks on NCAA 3c.

Those who agreed, responded that an NCAA guideline that recommended voluntary SCT testing was "Very Bad/Bad" (1.2%), "Very Good/Good"(9.3%), and "Neutral"(3.1%) respectively. Those who did not believe NCAA 3c would result in unfair treatment, responded "Very Good/Good" (27.0%), "Very Bad/Bad" (1.9%), and "Neutral" (5.0%) respectively. Those who were "Neutral" responded, "Very Bad/Bad" (2.7%), "Very Good/Good"(32.4%), and "Neutral" (17.4%) respectively.

There were significant differences ( $p=.004$ ) between those who perceived that NCAA 3c might result in unfair treatment and those who did not. Therefore, the study rejected the null hypothesis that perception of NCAA 3c resulting in unfair treatment of athletes with SCT was not associated with athletes' outlooks on NCAA 3c. Those who perceived that NCAA 3c would result in unfair treatment responded that an NCAA guideline that recommended mandatory SCT testing was "Very Bad/Bad" (0.0%), "Very Good/Good" (10.4%), and "Neutral" (3.1%) respectively. Those who did not believe that NCAA 3c would result in unfair treatment responded "Very Good/Good" (29.0%), "Very Bad/Bad" (0.8%), and "Neutral"(4.2%). Those who responded "Neutral" responded "Very Bad/Bad"(1.9%), "Very Good/Good"(32.8%), and "Neutral" (17.8%) in response to an NCAA guideline that would recommend mandatory SCT testing.

There were no significant differences ( $p=.176$ ) in perception that NCAA 3c might result in athletes being treated unfairly between ethnic groups. Therefore, the study failed to reject the null hypothesis that perception that NCAA 3c might result in athletes being treated unfairly will not differ significantly among ethnic groups. Of those who “Strongly Disagreed/Disagreed” (31.9%), 9.7% were African American and 22.2% were Caucasian. Of those who “Strongly Agreed/Agreed” (13.7%), 5.6% were African American and 8.1% were Caucasian. Of those who responded “Neutral” (53.4%), 13.7% were African American and 40.7% were Caucasian. Table 14 illustrates the association between perception that NCAA 3c might result in athletes with SCT being treated unfairly and voluntary/mandatory SCT testing and race/ethnicity.

#### *Hypotheses 6 and 12*

*Athletes’ perceptions of receiving less playing time is not associated with outlook on NCAA 3c.*

*Athletes’ perceptions of receiving less playing time if diagnosed with SCT will not differ among ethnic groups.*

There were significant differences ( $p=.007$ ) between those who agreed that they would receive less playing time if they were diagnosed with SCT and those who do not believe they would receive less playing time if they were diagnosed with SCT in attitudes towards an NCAA guideline that recommended voluntary SCT testing. The odds ratio was 2.14. Therefore, athletes who strongly disagreed/disagreed that they would receive less playing time if diagnosed with SCT were 2.14 times as likely to say that NCAA voluntary SCT testing was good. Therefore, the null hypothesis that athletes’ perceptions of receiving less playing time is not associated with outlook on NCAA 3c was rejected.

Those who agreed that they would receive less playing time responded that an NCAA guideline that recommended voluntary SCT testing was “Very Bad/Bad” (1.2%), “Very Good/Good” (8.1%), and “Neutral” (1.2%) respectively. Those who did not believe they would receive less playing time if diagnosed with SCT, responded “Very Good/Good” (29.0%), “Very Bad/Bad” (1.9%), and “Neutral” (6.2%) respectively. Those who were “Neutral” responded “Very Bad/Bad” (2.7%), “Very Good/Good” (31.7%), and “Neutral” (18.1%) respectively.

There were no significant differences ( $p=.101$ ) between those who believed that if they were diagnosed with SCT, they would receive less playing time and those who do not in attitudes towards an NCAA guideline that recommended mandatory SCT testing. Therefore, the study failed to reject the null hypothesis that athletes’ perceptions of receiving less playing time is not associated with outlook on NCAA 3c.

Those who agreed that, if diagnosed with SCT, they would receive less playing time responded “Very Bad/Bad” (0.0%), “Very Good/Good” (8.9%), and “Neutral” (1.5%) respectively. Those who did not believe they would receive less playing time if diagnosed with SCT responded “Very Good/Good” (29.0%), “Very Bad/Bad” (1.2%), and “Neutral” (6.9%) respectively. Those who responded “Neutral” responded “Very Bad/Bad” (1.5%), “Very Good/Good” (34.4%), and “Neutral” (16.6%) concerning an NCAA guideline recommending mandatory SCT testing.

There were no significant differences ( $p=.999$ ) in perception of receipt of less playing time if diagnosed with SCT. Therefore, the study failed to reject the null hypothesis that athletes’ perception of receipt of less playing time if diagnosed with SCT will differ among ethnic groups. Of those who “Strongly Agreed/Agreed” (9.7%) that unfair treatment might



result from NCAA3c, 2.8% were African American and 6.9 % were Caucasian. Of those who “Strongly disagreed/Disagreed” (36.3%), 10.5% were African American and 25.8% were Caucasian. Of those who responded “Neutral” (44.0%), 15.7% were African American and 38.3% were Caucasian (See Table 15).

Quantitative data analysis revealed five hypotheses with significant differences during the educational and ecological assessment (See Tables 5-6). These were 1) Hypothesis 1: Knowledge of SCT is not associated with athlete outlook on SCT testing. 2) Hypothesis 3: Perceived importance of knowing he/she has SCT is not associated with athlete outlook on SCT testing. 3) Hypothesis 5: Perception that NCAA 3c might result in athletes with SCT being treated unfairly is not associated with athletes’ outlooks on NCAA 3c. 4) Hypothesis 6: Athletes’ perceptions of receiving less playing time if he/she was diagnosed with SCT is not associated with outlook on NCAA 3c, and 5) Hypothesis 8: Perceived risk of having SCT will not differ among ethnic groups. Chapter 5 will highlight the themes from qualitative data collection that were utilized to further understand the findings from quantitative data collection.

Table 5  
*Research Questions: Educational and Ecological Assessment*

Research Questions	Hypotheses
What are the predisposing, enabling, and reinforcing factors that influence coaches and athletes' outlook on SCT testing?	<p><b>Hypothesis 1: Knowledge of SCT is not associated with athlete outlook on SCT testing</b></p> <p>Hypothesis 2: Perceived risk of having SCT is not associated with athlete outlook on SCT testing</p> <p><b>Hypothesis 3 : Perceived importance of knowing he/she has SCT is not associated with athlete outlook on SCT testing</b></p>
What are the predisposing, enabling, and reinforcing factors that influence coaches and athletes' outlook on NCAA guideline 3c?	<p>Hypothesis 4: Knowledge of NCAA 3c is not associated with athlete outlook on NCAA 3c.</p> <p><b>Hypothesis 5: Perception that NCAA 3c might result in athletes with SCT being treated unfairly is not associated with athletes' outlooks on NCAA 3c</b></p> <p><b>Hypothesis 6: Athletes' perceptions of receiving less playing time if he/she was diagnosed with SCT is not associated with outlook on NCAA 3c</b></p>
Do the predisposing, enabling, and reinforcing factors that influence coaches and athletes' outlooks on SCT and NCAA guideline 3c differ among ethnic groups?	<p>Hypothesis 7: Knowledge of SCT will not differ among ethnic groups</p> <p><b>Hypothesis 8: Perceived risk of having SCT will not differ among ethnic groups</b></p> <p>Hypothesis 9 : Perceived importance of knowing he/she has SCT will not differ among ethnic groups</p> <p>Hypothesis 10: Knowledge of NCAA 3c will not differ among ethnic groups</p> <p>Hypothesis 11: Perception that NCAA 3c might result in athletes with SCT being treated unfairly will not differ among ethnic groups</p> <p>Hypothesis 12: Athletes' perceptions of receiving less playing time if he/she was diagnosed with SCT will not differ among ethnic groups</p>

*Note:* Bolded hypotheses were found to be significant ( $p < .05$ )

Table 6  
*Summary of Significant Hypotheses*

Significant Hypotheses	Majority participant response	Total percent participants answering the majority response	Perceptions of NCAA Testing			P-value
			Participants answering very bad/bad	Percentage participants answering very good /good	Percentage participants answering neutral	
<b>Hypothesis 1:</b> Knowledge of SCT is not associated with athlete outlook on SCT testing	Adequate sickle cell trait knowledge	76.1	1.9	58.3	15.8	.015
<b>Hypothesis 3 :</b> Perceived importance of knowing he/she has SCT is not associated with athlete outlook on SCT testing	Strongly agree it is important to know SCT status	89.6	68.0	1.5	20.1	.001
<b>Hypothesis 5:</b> Perception that NCAA 3c might result in athletes with SCT being treated unfairly is not associated with athletes' outlooks on NCAA 3c	Neutral	52.5	1.9	32.8	17.8	.004
<b>Hypothesis 6:</b> Athletes' perceptions of receiving less playing time if he/she was diagnosed with SCT is not associated with outlook on NCAA 3c	Neutral	53.4	2.7	31.7	19.0	.007

*Note:* Perceptions of NCAA testing are perceptions of mandatory NCAA testing. Percentages of participants are the percentages of those with the majority response.

Table 7  
*Demographic Profile of Participants in Quantitative Phase of Study*

Variable	Frequency	Percent of Participants
<b>Gender</b>		
Male	158	61.0
Female	101	39.0
TOTAL	259	100.0
<b>Race/Ethnicity</b>		
Black/AfAm	72	27.8
NatHaw/OPI	1	0.4
White/Cauc	176	68.0
Hisp/Latino	5	1.9
Other	5	1.9
TOTAL	259	100.0
<b>Sport Played</b>		
Baseball	28	10.8
Golf	7	2.7
Women's Swim/Dive	13	5.0
Track and Field	27	10.4
Football	89	34.4
Women's Soccer	11	4.2
Men's Soccer	17	6.6
Volleyball	11	4.2
Women's Basketball	10	3.9
Men's Basketball	6	2.3
Women's Tennis	10	3.9
Men's Tennis	11	4.2
Softball	19	7.3
TOTAL	259	100

Table 8  
*Descriptive Frequencies: Adequate Sickle Cell Trait Knowledge; Questions 12, 13, 17, 18*

Question	Response Choice	Frequency	Percent
SCT Knowledge			
	Adequate (> 4 of 6 correct)	197	76.1
	Inadequate (<4 of 6 correct)	62	23.9
Question 12: I am at risk of having SCT			
	SD/D	156	60.2
	SA/A	35	13.5
	N	68	26.3
Question 13: It is important for an athlete to know if s/he has SCT.			
	SD/D	5	1.9
	SA/A	232	89.6
	N	22	8.5
Question 17: Perception of voluntary NCAA SCT testing			
	VB/B	15	5.8
	VG/G	178	68.7
	N	66	25.5
Question 18: Perceptions of mandatory NCAA SCT testing.			
	VB/B	7	2.7
	VG/G	187	72.2
	N	65	25.1

Table 9

*Adequate Knowledge of SCT Association with Attitudes Towards Voluntary/Mandatory SCT Testing and Race/Ethnicity*

Level of knowledge	Perceptions of testing			
	Very Good/Good	Very Bad/Bad	Neutral	
	Voluntary			
Adequate SCT Knowledge (>4 of 6 questions correct)	54.4(141)	4.6(12)	17.0(44)	
Inadequate SCT Knowledge (< 4 of 6 questions correct)	14.3(37)	1.2(3)	8.5(22)	p=.117
	Mandatory			
Adequate SCT Knowledge (>4 of 6 questions correct)	58.3(151)	1.9(5)	15.8(41)	
Inadequate SCT Knowledge (< 4 of 6 questions correct)	13.9(36)	0.8(2)	9.3(24)	p=.015
	Race/Ethnicity			
	African American	Caucasian	Total	
Adequate SCT Knowledge (>4 of 6 questions correct)	21(52)	54(134)	75(186)	
Inadequate SCT Knowledge (< 4 of 6 questions correct)	8.1(20)	16.9(42)	25(62)	p=.518
Total	29.0(72)	71.0(176)	248	

*Note.* Numbers on the left are percentages. Frequencies are included in parentheses.

Table 10  
*Perceived Risk of SCT Association with Attitude Towards Voluntary/ Mandatory NCAA SCT Testing and Ethnicity*

Level of Agreement	Perceptions of testing			
	Very Good/Good	Very Bad/Bad	Neutral	
		Voluntary		
Strongly Disagree/Disagree	42.1(109)	4.6(12)	14.1(35)	p=.126
Strongly Agree/Agree	10.0(26)	0.8(2)	2.8(7)	
Neutral	16.6(43)	0.4(1)	9.6(24)	
		Mandatory		
Strongly Disagree/Disagree	2.3(6)	43.6(113)	14.9(37)	p=.411
Strongly Agree/Agree	0.0(0)	10.8(28)	2.8(7)	
Neutral	0.4(1)	17.8(46)	8.5(21)	
		Race/Ethnicity		
	African American	Caucasian	Total	
Strongly Disagree/Disagree	12.1(30)	48.4(120)	60.5(150)	P=.001
Strongly Agree/Agree	9.3(23)	4.0(10)	13.3(33)	
Neutral	7.7(19)	18.5(46)	248	

Note. Numbers on the left are percentages. Frequencies are included in parentheses.

Table 11

*Perceived Importance of Knowing his/her SCT Status Association with Attitude Towards Voluntary/ Mandatory NCAA SCT Testing and Ethnicity*

Perceived importance of knowing SCT status	Perceptions of testing			
	Very Good/Good	Very Bad/Bad	Neutral	
		Voluntary		
Strongly Disagree/Disagree	0.4(1)	0.0(0)	1.5(4)	p=.001
Strongly Agree/Agree	65.3(169)	5.8(15)	18.5(48)	
Neutral	3.1(8)	0.0(0)	5.4(14)	
		Mandatory		
Strongly Disagree/Disagree	0.0(0)	1.5(4)	0.4(1)	p=.001
Strongly Agree/Agree	1.5(4)	68.0(176)	20.1(52)	
Neutral	1.2(3)	2.7(7)	4.6(12)	
		Race/Ethnicity		
	African American	Caucasian	Total	
Strongly Disagree/Disagree	0.0(0)	1.6(4)	1.6(4)	P=.205
Strongly Agree/Agree	27.4(68)	62.1(154)	89.5(222)	
Neutral	1.6(4)	7.3(18)	71.0(176)	
Total	29.0(72)	71.0(176)	248	

Note. Numbers on the left are percentages. Frequencies are included in parentheses.

Table 12  
*Descriptive Frequencies: NCAA 3c Knowledge and Questions 17, 18, 20, 21*

Question	Frequency	Percent
NCAA 3c Knowledge; Question 15		
No	146	56.4
Yes	112	43.2
Question 17: Perception of Voluntary NCAA SCT Testing		
VB/B	15	5.8
VG/G	178	68.7
N	66	25.5
Question 18: Perception of Mandatory NCAA SCT Testing		
VB/B	7	2.7
VG/G	187	72.2
N	65	25.1
Question 20: NCAA3c Results in Unfair Treatment		
SD/D	88	34
SA/A	35	13.5
N	136	52.5

Table 13  
*Knowledge of NCAA 3c Association with Attitudes Towards Voluntary/Mandatory SCT Testing and Race/Ethnicity*

Perceptions of testing			
Level of knowledge	Very Good/Good	Very Bad/Bad	Neutral
Voluntary			
Aware of NCAA 3c	30.9(80)	3.5(9)	16.2(23)
Not Aware of NCAA 3c	37.8(98)	2.3(6)	8.9(42)
Mandatory			
Aware of NCAA 3c	34.0(88)	0.8(2)	8.5(22)
Not Aware of NCAA 3c	38.2(99)	1.9(5)	16.2(42)
Race/Ethnicity			
	African American	Caucasian	Total
Aware of NCAA 3c	12.1(30)	31.2(77)	43.3(107)
Not Aware of NCAA 3c	17.0(42)	39.7(98)	56.7(140)
Total	29.1(72)	70.9(175)	247

*Note.* Numbers on the left are percentages. Frequencies are included in parentheses



Table 14

*Association Between Perception that NCAA 3c Might Result in Athletes with SCT Being Treated Unfairly and Voluntary/Mandatory SCT Testing and Race/Ethnicity*

Perception that athletes will be treated unfairly	Perceptions of testing			
	Very Bad/Bad	Very Good/Good	Neutral	
Voluntary				
PRECEDE Assessment Phase			Theme	
Strongly Disagree/Disagree	1.9(5)	27.0(70)	5.0(13)	p=.038
Strongly Agree/Agree	1.2(3)	9.3(24)	3.1(8)	
Neutral	2.7(7)	32.4(84)	17.4(45)	
Mandatory				
Strongly Disagree/Disagree	0.8(2)	29.0(75)	4.2(11)	p=.004
Strongly Agree/Agree	0.0(0)	10.4(27)	3.1(8)	
Neutral	1.9(5)	32.8(85)	17.8(46)	
Race/Ethnicity				
	African American	Caucasian	Total	p=.176
Strongly Disagree/Disagree	9.7(24)	22.2(55)	31.9(79)	
Strongly Agree/Agree	5.6(14)	8.1(20)	13.7(34)	
Neutral	13.7(34)	40.7(101)	54.4(135)	
Total	29.0(72)	54.4(135)	248	

Table 15

*Perceptions of Receipt of Less Playing Time Association with Attitude Towards Voluntary/Mandatory SCT Testing and Race/Ethnicity*

Perception of lost playing time	Perceptions of testing			
	Very Bad/Bad	Very Good/Good	Neutral	
Voluntary				
Strongly Disagree/Disagree	1.9(5)	29(75)	6.5(16)	p=.007
Strongly Agree/Agree	1.2(3)	8.1(21)	1.2(3)	
Neutral	2.7(7)	31.7(82)	19.0(47)	
Mandatory				
Strongly Disagree/Disagree	1.2(3)	29.0(75)	7.3(18)	p=.101
Strongly Agree/Agree	0.0(0)	8.9(23)	1.6(4)	
Neutral	1.5(4)	34.4(89)	17.3(43)	
Race/Ethnicity				
	African American	Caucasian	Total	p=.999
Strongly Disagree/Disagree	10.5(26)	25.8(64)	36.3(90)	
Strongly Agree/Agree	2.8(7)	6.9(17)	9.7(24)	
Neutral	15.7(39)	38.3(95)	54.0(134)	
Total	29.0(72)	71.0(176)	248	

## CHAPTER 5

## Phase II: QUALITATIVE ANALYSIS FINDINGS

*Participants**Focus Groups.*

Focus group 1 consisted of nine total participants. All self identified as Caucasian. Ten agreed to participate. However, one was unable to attend because of a schedule conflict. There were three males and six females who attended. Three of the athletes were football players, four were volleyball players, one was a cross country runner, and one was a basketball player.

Focus group 2 consisted of nine total participants who self identified as African American. Ten agreed to participate. However, one was unable to attend because of a family conflict. There were four males and five females who attended. Four of the athletes were football players, one was a volleyball player, and four were basketball players.

Focus group 3 consisted of 11 total participants. All were participants in one of the first two groups who volunteered to return for the third group. Group 3 was a follow-up group to groups 1 and 2. This group was a mixed ethnicity group to determine if there was variation in participant responses as a result of the mixed ethnic composition of the group. The purpose of the group was also to gain clarity on responses given during groups 1 and 2. There were two males and nine females who attended. Two of the athletes were football players, one was a cross country runner, three were volleyball players, and five were basketball players. Table 16 illustrates the composition of the three focus groups.

Table 16  
Focus Group Composition

	Demographic Variables				Sport Played/Number Representing Sport	Total
	Male	Female	African American	Caucasian		
Focus Group 1	3	6	0	9	FB(3) VB(4) CC(1) BB(1)	9
Focus Group 2	4	5	9	0	FB(4) VB(1) BB(4)	9
Focus Group 3	2	9	5	6	FB(2) VB(3) CC(1) BB(5)	11

Note: FB=Football; VB=Volleyball; CC=Cross Country; BB=Basketball

The following section will outline the qualitative findings based upon phases of the PRECEDE-PROCEED (Green & Kreuter, 1999) model of program planning. The section begins with a review of the development of the NCAA mandated sickle cell trait screening policy. Current sickle cell trait screening practices at Georgia Southern University will be described. This will be followed by themes that emerged from the social assessment/situational analysis, educational and ecological assessment, and intervention alignment will be displayed respectively. The section will conclude with the hematologist's perspective.

#### Development of Mandatory Sickle Cell Trait Screening Policy

The changes from no formal recommendation of sickle cell trait screening to a formal recommendation of screening to mandatory SCT screening policy began with recommendations from the National Athletic Trainer's Association. The National Athletic Trainer's Association (NATA) published a Consensus Statement (2007) entitled: *Sickle Cell Trait and the Athlete*. The purpose of the statement was to raise awareness of exertional rhabdomyolysis (explosive muscle breakdown) in sickle cell trait carriers and provide measures to reduce the risk of

exertional collapse related to SCT. This statement is the basis for the NCAAs amendment to Guideline 3c. The NATA recommends testing for the SCT status of all athletes during the pre participation physical examinations. Further, they recommend the following:

This marker is a base element of personal health information that should be made readily available to the athlete, the athlete's parents, and the athlete's healthcare provider, including those providers responsible for determination of medical eligibility for participation in sports (National Athletic Trainer's Association, 2007).

In 2010, the NCAA adopted new SCT testing legislation. The NCAA developed a question and answer document to be utilized by NCAA Division 1 membership in explaining Proposal 2009-75-B. The following answer was written to the question, "Does NCAA Division 1 legislation require sickle cell trait testing?"

In Division I, legislation has been adopted that requires institutions, as part of the medical examination required before athletics participation, to include a sickle cell solubility test, unless documented results of a prior test are provided to the institution or the student-athlete declines the test and signs a written release. This legislation is effective as of August 1, 2010 and is applicable to student-athletes who are beginning their initial year of eligibility and student-athletes trying out for a team, including transfers. Returning student-athletes are not required to be given the test.

The NCAA policy mandates pre-participation screening. However, it lacks subsequent policy that mandates protection against possible discrimination against athletes who are

diagnosed with SCT. The NCAA has developed an educational video that explains sickle cell trait as it relates to the athlete. The NCAA has also developed two handouts that explain sickle cell trait and its relation to athletic activity. One is designed for coaches. One is designed for athletes. However, beyond these educational materials, there is not a policy that outlines post diagnosis procedures. It was indicated, during qualitative data collection, that there are not clear guidelines as to specific procedure for pre-participation screening. Georgia Southern University began screening athletes under the recommendation (before there was a mandated policy) in August of 2009. It was determined that there was not a clear outline of pre-participation screening procedure that was distributed by the NCAA. However, Georgia Southern University was found to perform a logical process for pre-participation SCT screening, diagnosis, and follow-up.

#### Current Sickle Cell Trait Screening Practices at Georgia Southern University

The head athletic trainer for Georgia Southern University was interviewed to determine current health education practices as they relate to sickle cell trait. She described procedures from pre-participation screening to diagnosis of SCT in a student athlete.

#### *Sickle Cell Trait Screening Procedure.*

Georgia Southern University screened all of its student athletes, regardless of ethnicity, in 2009. Coaches were given education about sickle cell trait and precautions such as games at elevation and strenuous exercise, if one of his/her players was found to have a positive test for sickle cell trait. Coaches were asked to sign a form indicating that they had received the information.

### *Procedure for the Sickle Cell Trait Positive Athlete*

#### 1. The Athlete With Sickle Cell Trait and Coaches are Informed of the Test Results

We tell that individual and then we educate the coaches [about the test results] so the coaches can also be aware of what's going on but we don't do that until we educate the athlete first.

#### 2. Follow-Up Testing is Performed

If they come back positive they go back for another test to make sure that it's positive and to [determine] how many hemoglobin S that they have in their system and after we know that, that's [determination of the number of hemoglobin S in the athlete's system] for blood work purposes

#### 3. The Athlete With Sickle Cell Trait and Coaches are Educated

We educate the athlete as to what it is, what it might mean and what we are goanna do differently, what it means and then we have to meet with the doctor.

#### 4. Physician-Based Education and Genetic Information

[The doctor] sits down and lets them know what it means if they marry somebody with it and then we sit down and educate the entire coaching staff [of that athlete's team] and what it means and what they are to help us look for so in the larger teams it's more important because we can't keep our eye on every single person. So like for football they break off into groups and the players in their positions so that the coach can help monitor [the athlete with SCT].

The head athletic trainer described current sickle cell trait practices at Georgia Southern University. This information provided contextual information for further study with athletes and coaches. The following are the themes that emerged from the athletes' perspectives.

#### Social Assessment and Situational Analysis

##### *Pre-Participation Sports Physical-Just Do It!*

Each of the focus groups began by asking athletes a general, non-threatening question about what normally happens during a pre-participation sports physical. Participants described the typical sports physical by responding with answers such as *"heart rate, memory tests"*, *"check your range of motion"*, *"concussion test"*, *"eyesight"*, and *"height and weight"*. The knowledge and understanding that they had undergone sickle cell testing was not evident since only one participant mentioned that a sickle cell test was performed. She stated, *"Oh yeah, they started that sickle cell stuff this year."* It seemed that the physical had become merely a "sports ritual" and athletes did not really think about the tests or what the results might reveal. One participant said and others agreed, *"you gotta get it done."* Athletes were found to have a "just do it" attitude when it came to sports physicals. However, after further questioning it became evident that at some level they were concerned about their health screening results.

##### *Athletes' Want Health Education and Feedback*

When asked how they were informed of the results of the sports physical screening tests, participants reported that they were not told about the results of their pre-participation sports physicals unless something was wrong. One participant said, *"No news is good news."* Another participant stated, *"If you don't get nothing back that means you good. Really you*

*don't wanna hear nothing...just let me go on about my business...just as long as you don't say I'm bad...I'm good."*

As the athletes reflected more upon the pre-participation sports physical process, they revealed that the initial sports physical, when entering their freshman year was comprehensive and then as they progress throughout their college athletic career, the physical process seems to become less thorough. One athlete reported, *"We don't get a physical every year now."* Another participant agreed, *"Yeah, they do your eyes and check everything when you first come in and then after that they're like 'just sign the papers' and you're ready to go for the next season"*. One participant said, however, *"I really don't mind it not being as thorough after the first year. Don't keep checking me for the same thing."*

Some of the athletes realized that they actually would like to learn about the screening tests themselves as well as the results of the pre-participation sports physical. One participant said, *"I would definitely like to get a handout...something to take home...something I could have, look at, reference."* Another athlete said, *"We would like to understand what we're being tested for."* One athlete explained the process of being tested for SCT and the lack of information concerning the test:

I think they should really tell you what you are being tested for because last year when they told me I had to get a sickle cell test, I was like 'what am I goanna do'?...and they were like mostly black people get it and I was like...oh ok...well I'm good then...I don't need to worry about anything. But they tell you what it is and tell you the symptoms and you're like 'oh that could be [bad]'. People actually need to know what they're getting their blood taken for instead of saying...well you probably don't have it but we



gotta do it anyway type of thing. That's the biggest thing. Nobody really knew [what we were being tested for]. We just kinda did it.

Therefore, athletes realized that they did want to be more informed about the tests included in the sports physicals as well as the results of those tests. However, when asked about sharing the information with their coaches, concerns surfaced immediately.

#### *Athletes Have Cognitive Dissonance About Sharing Health Information*

An athletes' main concern is loss of playing time related to injury or other health issues. Focus group participants often related loss of playing time with their coaches' awareness of their injuries or other health issues, which resulted in athletes not being totally forthcoming about their health. They were conflicted about what to do if a health concern arose. They felt that coaches should know pertinent details about their health. However, they also felt that revealing any problems would result in lost playing time.

All athletes agreed, "*they [coaches] need to know [about health conditions].*" One participant said, "*he'd [coach] be understanding [if I had SCT or any other health issue].*" Another stated, "*it's [telling the coach about your health problems] for your own good, for your own protection, for your own health*". Therefore, participants saw their coaches as individuals who would understand about injuries or health conditions and protect them from further harm. However, when asked if the revelation of health information might affect playing time, athletes overwhelmingly agreed that they would receive less playing time if coaches knew of their health issues. Athletes reported,

When I came in I had knee problems, I had ankle problems, I had shoulder problems and I knew that but they [coaches and athletic trainers] didn't know.

I'm not goanna be like.. 'oooh did you check my shoulders cause they suck?!' I'm not goanna volunteer my injuries.

Another said,

...personally, I wouldn't say anything [to the coaches or athletic trainers] until they saw something was wrong.

Another agreed,

...It's like, either way it's a lose-lose. If you tell 'em before, it's goanna look like you're making an excuse. If you tell them afterwards, it's goanna look like an excuse. So it's like which one do I do?

Athletes concealed health issues from coaches. The internal conflict between desire to play and need to remain healthy was a consistent struggle for athletes. Athletes appear to be caught between the coaches need to keep them playing and the athletic trainers desire to keep them healthy. Participants revealed that there's no consistency across coaches and athletic trainers or sports teams concerning who makes the final decision whether or not the athlete plays when injury or illness is known or expected. An athlete stated,

...with football, your position coach won't just bench you. He will come talk to you and ask you what's wrong. 'Do you think you can go? If you can go; fine. If you can't let me know.' But he's not just goanna bench you because he talks to the trainer. The trainer might tell him, 'he don't need to go,' but then he will go talk to you and ask you 'can you go?' and if you can go [you will play].

Another athlete responded, *“Our coach doesn’t do that. He asks the trainer. Regardless of what we think we can do or not, if the trainer tells the coach no she can’t go, then [we won’t play].”*

Another also commented on the coach-athletic trainer dynamic, *“I know our coach respects what the trainer has to say, but you can tell she doesn’t like it.”* Athletes also shared that they sometimes do not reveal injuries even to the trainers for fear of lost playing time:

Our coach would say ‘can she play or can she not’. Our athletic trainer wasn’t as good as [another athletic trainer] and she would just take you out. I had gotten minor injuries and I probably should have gone in but [you don’t want to tell the trainer]. I didn’t want to take the risk of never coming back. I don’t even want to go in and see an athletic trainer because I don’t want to be taken out for things that are ridiculous.

#### Educational/Ecological Assessment

##### *Athletes had Inadequate Knowledge of Sickle Cell Trait*

After inquiring about the daily routines and concerns of the athletes, questions became more specific to the athletes’ knowledge of sickle cell trait (SCT) and NCAA recommendation 3c. Athletes had limited knowledge of SCT and they were unaware of the history of SCT as it relates to discrimination. Responses were general, *“It’s predominately in African Americans.” “It’s something in the blood,”* and did not indicate any in-depth understanding of the disease although they knew that athletes with SCT might get *“winded quicker.”* One athlete stated, *“It’s not as serious as the actual disease.”* Another demonstrated basic knowledge of the inheritance pattern of the trait by stating, *“It’s not always passed down through the generations. You know*

*your father might have it [SCT] but don't mean you goanna have it...and even both your parents might have it."*

Although some athletes had basic knowledge of SCT, they had many misconceptions about the trait as well. One participant stated, "*...their blood cells are like split in half or have holes in them or something.*" Another stated, "*...with [the sickle cell] trait, you have the potential to carry the disease.*" Participants made comments that illustrated their lack of understanding of how traits are expressed in one's DNA (Deoxyribonucleic Acid), "*If you're a carrier, you have spots of it throughout your body and it's not necessarily full on spread.*"

African Americans believed that SCT occurs in a specific type of blood and that Caucasians are not susceptible to SCT as evidenced by the following statements, "*Isn't it in type O blood? A lot of African Americans have type O blood.*" and "*Caucasians can't get it.*"

#### *Athletes had Inadequate Knowledge of being tested under the new NCAA 3c Recommendation*

Athletes had limited, to no, knowledge of the NCAA recommendation 3c about screening for SCT. All athletes were unaware of the recommendation until this year (2010) because Georgia Southern had recently began testing all athletes for SCT after the NCAA recommended that all athletes be tested for sickle cell trait. Some were still unaware. One person stated, "*I just found out just now [during the focus group].*" Another explained, "*that's when they drew blood.*" To which the former replied, "*that's what that was?*" Other athletes agreed that they were unaware as well.

#### *Athletes Thought Sickle Cell Trait Would Affect Their Playing Time*

Athletes held negative perceptions of SCT. When asked how they would feel if they were diagnosed with SCT, one participant responded, "*screwed.*" Another stated, "*Well, you*

*know we are all in Division I athletics because we're competitive...and to be taken out because of something you have...it sucks."* Because of this competitive nature, from the athletes' perspectives, anything that affected playing time was seen as negative. *"I would feel upset because that means that I would be looked at differently and even though I may say I'm okay...if the trainer doesn't think I'm okay...I still have to sit out...and just sitting out, you feel like you're useless sometimes."* Another player commented, *"It would just feel like another thing holding you back."*

Athletes felt that health issues, like SCT, would affect their playing time. However, these opinions did not translate to negative perceptions of NCAA mandated SCT testing.

#### *Athletes have Positive Perceptions of the NCAA 3c recommendation*

Athletes did not express any negative perceptions of the NCAA 3c recommendation. Athletes are accustomed to carrying out NCAA mandates. Therefore, they did not perceive NCAA 3c as being different from any of the other guidelines they had to abide by to play collegiate athletics. When asked how they felt about the 3c recommendation participants overwhelmingly responded, *"It's good."*, *"It's smart."* Athletes strongly supported mandatory testing. One said, *"I would support mandatory testing. It's just good to know. Period!"* One athlete linked mandatory testing to positive health practices, *"I think it's good because you'd be surprised how many athletes or people just in general don't go to the doctor on their own. So, I think it's good to make us [more aware]."* Another athlete agreed that NCAA recommendation 3c was seen as just another NCAA mandate.

I don't think it affects a lot of athletes because they are just gonna look at it as something else we gotta do for the NCAA so let's go on and get it done and go on

about our business. Cause in the pre-season you gotta do all this and that, fill out this and that...so you're like alright...something else we gotta do. Let's get it done and get the season on with.

Athletes believed that NCAA mandated testing was smart and they readily agreed with it. The next set of questions asked participants about their perspectives of the link between NCAA mandated SCT testing and racism.

### *Race on the College Campus and in Athletics*

After determining athletes' perspectives about SCT and NCAA3c, the focus group facilitator explained that there was fear from the sickle cell community that NCAA 3c might result in discrimination toward SCT carriers and possibly African Americans since sickle cell primarily affects that ethnic group. The questioning began by asking participants about racism on campus and then specifically in college athletics. Both African American and Caucasian athletes separated "campus" from "athletics". Caucasian athletes believed that African American athletes were treated differently on campus: *"Well on campus...there's like African American football players in my classes and they get away with murder...they get favored."* Another agreed, *"I have some black football players in my classes who have gotten away with so much its' ridiculous...like not doing work and before [coach] came they got away with everything. They were never punished."*

None of the African American athletes felt that racism existed on Georgia Southern's campus. African American participants spoke as if racism does not currently exist and even expressed shock that the question was asked. One participant replied, *"Maybe it's 2010 and people just don't care no more. If you asked us in 1960 I might be like I don't go to the white*

*hall...I go to the black café. I believe that if anybody tries to take this [NCAA 3c] as a racially discriminative thing...that's just ignorance."*

Another athlete summarized his/her rationale for why athletes were not treated differently by saying,

I say no they're not treated different because it's on the basis of whether or not you're good at your sport. If you play football and you're African American or Caucasian and you're good at your sport and you're on billboards and stuff they are goanna treat you the same. It's just like on a level of how good you are.

Another said, *"Just win...really at this level it boils down to one thing...just winning cause it's a business now. Its money...you talkin' revenue. So if you not winnin', you not getting the job done."*

Although African American athletes did not perceive blatant racism on campus, they were familiar with the inherent nature of racism in sport meaning that African Americans and Caucasian athletes have roles in sport in which they are stereotypically placed (i.e. African American females are sprinters, Caucasian females are long distance runners). Caucasian athletes perceived that there were forms of reverse discrimination within college athletics.

#### *Perceptions of Reverse Discrimination*

Similar to African American athletes, White athletes were unable to provide any examples of overt racism on campus. However, they did identify differences in how athletes are treated based on race. One White participant recounted his experiences:

I feel like that they [GSU coaches] kind of expect more of the African American kids or something like that because I think they feel like they are a little bit more

naturally... a little bit more talented. I think it's [discrimination] the other way around actually. I've experienced it [discrimination].

Another White athlete reflected upon the inherent nature of racism in sport:

With track, it's basically like a black thing and a white thing...black girls are known as sprinters, white girls are known as distance runners. So when you see a white sprinter, you're like 'Oh Go white girl' and that's basically like what it is with us...so you experience it [racism].

Athletes described their housing arrangements and how they were often segregated as an example of covert racism:

At first it [housing] was completely segregated like it was you know four white people in a room and it was like people weren't even in the same position or on the same side of the ball...it was like they made sure it was like four white people with each other...four black people with each other.

Caucasians perceived that African Americans were treated differently within sport.

African Americans perceived this difference as well. However, their perspectives of the difference were markedly different.

#### *African American Athletes do not Perceive Racism*

For African American study participants, being African American in college athletics was not a hindrance or source of discrimination. They felt that they, as African Americans, were essential to college sports and that the coaches and athletic director were well aware of that fact. When asked if African American SCT carriers might be discriminated against, one athlete boldly stated,



Guaranteed the athletic director gone be like ya'll can't discriminate against these black boys. You need to go get some black boys on this field.

Another agreed and said,

Yeah, cause the athletic director gone be thinking like that coach...I got four white defensive backs...some things wrong! He might have sickle cell, but put him on the field. We gotta win. He been playin' for four years, so why can't he play now with sickle cell?

Both of these athletes agreed that they had heard coaches make racist remarks. *"I done heard some coaches be like, 'Yo I will never have a white safety.'" to which another agreed, "Coaches say I will never have two white safeties."* These athletes recognized the inherent nature of racism in athletics as well: *"It's just a stereotype. You don't see too many Caucasian defensive backs in football at any level. That's just how it is! That's how society has the sport set up."*

Caucasian and African American perspectives of racism were noticeably different. However, as athletes, their lives parallel each other greatly, regardless of race. Therefore, the next set of questions asked participants to describe a typical day in the life of an athlete.

#### Intervention Alignment

Athletes' lives are considerably different from the college student who is not a member of an athletic team. Therefore, it was necessary to learn more about their daily routines to inform the optimal timing of a SCT educational intervention.

### *Timing of Education is Critical*

Athletes were asked about their typical schedules and their ideal health education program. It was important to examine the daily lives of the athlete to determine when they might have time to attend a health education session. When asked about their daily lives athletes agreed, *“Wake up, work out, school, work out, study hall, somewhere you eat.”* A detailed account of a typical day was given by an athlete:

Depending on the day, I might have practice in the morning, at like seven. Then I go to class...I have to wake up at six in order to get there. Then we'll have practice for like two-and-a-half to three hours. Then I go to class all day because my schedule has to revolve around that. And that's a good day because I practice in the morning. If I have practice in the evening...then I have class all day, then I'll have practice, then we'll go to weights, and then I'll go home and do homework. But my day starts at like eight and won't end until six. If you have study hall then it's longer.

Athletes agreed that the education session should be mandatory because of their busy schedules:

*“They better go on and say this [health education] is an NCAA mandatory thing. Cause if it's optional, that option is not gone be accepted.”* They agreed that the best time would be during the preseason: *“At pre-season meetings, we gotta do this meeting...schedule one of those times to do the little health thing while we gotta sit there and listen. That's goanna be your best bet. Anything else is a waste of my time.”*

### *Interactive, Athlete-Specific Education*

Athletes desired information that was interactive and athlete/sports specific. Some athletes wanted “a handout” or “DVD”. However, others disagreed stating, “*the one thing about DVDs is that you goanna fall asleep. It has to be some kind of interaction with a discussion afterwards.*” Participants recognized that everyone does not want the results of sports physicals or other health examinations. Therefore, they suggested a website that could be “*updated as you progress in your years*” so that they have access to their health information if they want it. One athlete illustrated the need for the website:

I broke my foot and I gave the x-rays to the trainers and I still haven't heard back. So, I hope I'm okay 'cause obviously something could be wrong but they obviously don't think it's that big of a deal but what if I could be doing preventative steps to take care of it. I have no idea how those x-rays looked or anything...not even if they were good...so maybe if it was online, both of us [athlete and athletic trainer] could access it.

During qualitative inquiry with athletes, it was found that athletes are accustomed to the typical sports physical. Therefore, the addition of SCT was not viewed by athletes as something negative. Athletes generally lacked knowledge of SCT and were apathetic about sports physicals. However, they were concerned at some level about the results of the tests because of the implications it might have on their playing time. Athletes had little, to no, knowledge of the NCAA recommendation or being tested under it. They also had positive attitudes towards testing because they are accustomed to compliance with NCAA mandates. Athletes did not recognize racism on campus. However, both African Americans and Caucasians

recognized the inherent nature of sport. Athletes agreed that timing of an intervention was critical and that the most effective interventions were interactive and athlete-specific. Table 17 illustrates the themes that emerged from qualitative inquiry with the athletes. The following section highlights themes that emerged from in-depth interviews with coaches.

Table 17

*Qualitative Data Analysis Themes*

Social Assessment/Situational Analysis	<ul style="list-style-type: none"> <li>• Pre-Participation Sports Physicals- Just Do It!</li> <li>• Athletes' Desire for Health Education/Feedback</li> <li>• Athletes' Internal Conflict between Sharing Health Information and Loss of Playing Time</li> <li>• Coach-Athlete-Athletic Trainer Dynamic</li> </ul>
Educational/Ecological Assessment	<ul style="list-style-type: none"> <li>• Inadequate Knowledge of SCT</li> <li>• Inadequate Knowledge of NCAA 3c</li> <li>• Negative Perceptions of SCT</li> <li>• Positive Perceptions of NCAA 3c</li> <li>• Racism in Athletics               <ul style="list-style-type: none"> <li>○ Caucasians Perceive Reverse Discrimination</li> <li>○ African American perceived athleticism as a "Protective Factor"</li> </ul> </li> </ul>
Intervention Alignment/Policy Assessment	<ul style="list-style-type: none"> <li>• Timing is Critical</li> <li>• Interactive (adult learner)</li> <li>• Athlete-Specific</li> <li>• Education should be mandated by the NCAA for coaches and athletic trainers</li> <li>• NCAA Division 1 Proposal-2009-75-B has potential implications for discrimination towards SCT carriers</li> <li>• Policy has not been made that protects athletes from possible negative implications</li> </ul>

### The Coaches' Perspectives

This section highlights the key themes that emerged from in-depth interviews with four head coaches at Georgia Southern University. Overall, coaches had limited knowledge of SCT, similar to that of athletes. Coaches also had positive perceptions of NCAA 3c. They indicated

that they would support sickle cell trait carriers and were concerned for the athletes' health in general. Each of these themes has implications for the future of the athlete with sickle cell trait.

### *Coaches inadequate Knowledge of Sickle Cell Trait*

Like athletes, coaches knew basic information about SCT. However, the information was limited. When asked about sickle cell trait knowledge, coaches responded, "...they [athletes with SCT get] winded quicker", "light headed or overwinded", and "it affects African Americans more than any other race." Coaches expressed that they had little knowledge of the disease outside of this information by saying: "...we are just in the process now of starting to understand about it a little bit." When asked about knowledge of SCT another coach simply stated, "[We know] very little. Only what the trainers have told us." It was concluded that coaches lacked fundamental knowledge of SCT. Despite lack of knowledge of the trait, coaches supported mandatory SCT testing for athletes.

### *Coaches Support Mandatory Sickle Cell Trait Testing for Athletes*

Coaches believed that mandatory sickle cell trait testing through NCAA 3c was beneficial to their athletes' health. One coach stated, "I support it [NCAA sickle cell trait testing]. I think it should be mandatory." Another coach had similar views: "...they have mandatory testing now. I think it's great. I think the more we know about their history before they get out there the better. So I am for the mandatory testing." Another coach illustrated his reason for supporting mandatory testing by saying: "I like mandatory simply because some of the kids like in our case they didn't know they had it and had we not forced all of them to go through the testing it would not have shown up." Therefore, it was concluded that coaches supported mandatory SCT testing because they believed it would be beneficial to the health of their athletes. Coaches also indicated that they would support an athlete who was diagnosed with SCT.

### *Coaches Support Sickle Cell Trait Carriers*

All coaches said that they would support an athlete on their team who was diagnosed with SCT. One coach stated, *"I don't care if they were all sickle cell we'll monitor them and we'll watch them."* When asked about how the coach would feel if an athlete on his/her team was diagnosed with SCT, a coach stated, *"I think awareness is one of the best things I could possibly have when dealing with my athletes; and so I think I would feel... good because now I kind of know what they are dealing with."* Coaches developed bonds with their athletes and were therefore supportive of those who were already on their teams. When the question was geared towards the recruitment of athletes with SCT, coaches were supportive, but more reluctant. When asked if he/she would recruit an athlete with SCT, one coach explained the relationship between athlete health and scholarship dollars:

I don't know if you can invest scholarship dollars and if you go out and invest in an athlete that's injured or hurt too much, your program can fall apart and giving scholarships as a head coach you know you gotta treat scholarships like gold. I mean I like giving a guy a scholarship, but I have a responsibility to this university to our alumni and our boosters to take young men into the program that when I offer a scholarship to a young man he is the total package so that is a tough one, a tough one. I wouldn't discriminate against a young man once he is in my program if I found out afterwards but I can't say that I'd just go out and recruit ten individuals that had sickle cell trait. That would be tough.

Another coach expressed the need for a strong athletic training staff when recruiting individuals with SCT.



As long as I knew I had the staff and the training facilities that were on top of things and understood it [sickle cell trait], I would have no problem recruiting that athlete. I would not treat them a bit different. But if I wasn't equipped where I could be able to deal with it whether it be personnel or whatever then certainly I wouldn't be able to recruit them but fortunately I am in a situation where I can so it wouldn't affect me into the least.

It was concluded that coaches are supportive of athletes who are currently on their teams.

Coaches may be reserved on some levels about recruiting athletes known to have SCT.

However, they are genuinely concerned about their athletes' overall health.

#### *Coaches are Concerned About Their Athletes' Health*

Coaches shared that they constantly think of the athletes' health. Coaches listed "dehydration," "heat exhaustion," and "heart problems" as their biggest concerns. One coach expressed concern for the athlete by saying, "*You know winning a game or having a full team in practice is not more important than a young man's life.*" When asked if he/she ever thought of the athletes' health, one coach replied,

All the time. With what we put them through on a daily basis the physical nature of this level and the intensity the stress that is involved we are constantly on top or their health issues. No question there. We don't want to put anybody out there to be put into a position to be hurt or injured that there may be something already looming you know. We want them out there 100%.

When asked if s/he would be willing to attend an education session to learn about a health issue that surfaced as a result of a pre-participation sports physical a coach stated,

Why sure. If I have been with an athlete and they are giving me basically their life for four years and with what I put them through as a college athlete I certainly want to be there to get the best out of them. I can't expect them to give me 100% if I am not going to give them 100% of my time. And I want to understand what's going on with them and work toward what I can do to get the maximum out of them. Certainly, whether on the [playing surface], or just off the [playing surface]; whether in the classroom, or life.

Each of the coaches expressed concern for the athletes' health. They articulated that they would be willing to attend education sessions about an athlete's health. However, awareness of athletes' health issue raises concerns about confidentiality.

#### *Confidentiality Issues*

Coaches agreed that athletes' health information should be held in confidence. They stated that they were not told about athlete health information. However, this was contradicted by later statements. When asked about concerns about coaches or athletic trainers knowing an athlete's health information, one coach said,

I think we [coaches] need to be informed to the extent of, 'okay this person can or cannot do something'. I don't feel like it's always our right to have the intimate details. So I would say that given enough information to where we can move and help with their safety but not so much that it covers all their business.

Another coach had similar views:

[Information should be given to coaches on an] as needed basis because I think you need to protect that athlete as much as possible and they may not want to have it out and they need to be protected as much as possible. Medically, we don't know anything as a staff they don't tell us other than there may be a problem or something showed up that's all we know because of the laws they govern that so just the trainers actually just that administer the tests they will know they will discuss it with the athletes or whatever the doctors find they will discuss with the athletes themselves.

However, another coaches' comments indicated that medical information was immediately given to the coaches as health issues are discovered during a pre-participation sports physical:

Usually if there is nothing wrong, then we don't hear anything. But if something comes up... heart problem, irregular heartbeat, high blood pressure, then that person is told immediately, coaches are notified immediately, and then they try to treat whatever the problem is.

Another coach expressed that they are given athlete health information that is specific to sickle cell trait as well by saying, *"They identify those on our team that have the trait so that we can watch out for those signs and we just monitor them very closely."*

Coaches indicated that they believed the athletes' health specific information should be kept confidential. However, they also indicated that they were made aware of specific issues that arose as a result of pre-participation sports physicals. Coaches agreed that if they did have

to participate in an education session to learn more about these health issues, the pre-season would be the best time.

*Pre-Season is the Best Time for Education Sessions*

All coaches agreed that the pre-season would be the best time for a health education session. All teams have different seasons. Therefore, the pre-season was determined to be during the week before school starts because this is the time when athletes are completing other mandatory pre-season tasks and are attending pre-season meetings. One coach said,

I would definitely do it at the beginning of the season. We are not in school right now [the beginning of August] but they are here so they don't have classes you know what I mean it's very free right now.

Another coach agreed by stating,

Probably right before school starts would be the best time within a week or two of actual school starting because you are already in preparation for getting stuff ready for kids coming in and for that year but the kids aren't in school yet so you have more time during your day I guess.

Another coach expressed the difficulty of having a session in-season by stating,

If they could do it around six in the morning or if they could do it eight o'clock at night or nine o'clock at night I could probably make time right now during the season but other than that we wouldn't have time.

Coaches also indicated that this session should be given by someone who is familiar with the lifestyle and physique of an athlete. Coaches stated that the athletic trainers were

their greatest resources and also agreed with the athletes that the session should be interactive.

For me it's good because they [athletic trainers] know the life of an athlete and how they think. They are with them every day. It's just like there's an athlete going to a general practitioner for an athletic injury, most general practitioners aren't goanna know that an athlete's body is just totally different and they need a specialist in that area like a sports doctor for rehab and you know for surgeries or whatever because they [sports doctors] know they [athletes] are just more fine tuned than the average person. I think that training staff is right on top of the college athlete's world.

Another coach also viewed athletic trainers as an important educational resource and stated,

They [athletic trainers] did it [educated the coaches and athletes] this year with the sickle cell trait and I'm sure they're goanna do it again and try to do an even better job than they did last year. I think our trainer does a very good job of that [educating and finding resources for education].

Another coach commented on the importance of the athletic training staff by stating, *"the athletic trainers are the best resource I think in terms of medical issues because they know our kids so well and their medical histories and they've got a good handle on that."*

Another coach expressed the need for an athlete specific as well as interactive education session by stating,

If you have an instructor or leader whoever is up giving this information with high energy that knows a little bit about them [the student athlete] and their

sport, they are goanna remember it for as long as you need them to. So I would say have a hands-on 40-minute session. Something that is gonna get them active and go from there. I think that's a good way to do it.

Coaches agreed that the best time for a health education for them as well as their athletes was during the two weeks prior to the start of the fall semester of school. They agreed that the information included in the health education session should be interactive as well as athlete-specific.

After obtaining this information, it was also important to gain the insights of a hematologist concerning necessary components of a sickle cell trait education program to determine if there were any gaps in current practices. The following section is the summary of findings from the interview with a hematologist who specializes in sickle cell disease.

#### The Hematologist Perspective

One hematologist, who specializes in sickle cell disease and trait, was interviewed for the study. He was interviewed to determine his perceptions of mandatory sickle cell trait screening for athletes and to determine recommendations for intervention from the perspective of a medical doctor. The hematologist had recently gone to a National Institutes of Health (NIH) meeting where the topic of sickle cell trait screening and the athlete was discussed. He summarized the results of the meeting by saying,

There were scientists, hematologists, also psychologists and social workers [in attendance]. The summary is number one; we should be looking into sickle cell trait scientifically in detail as to how these things [sickle cell trait related deaths] happen. But in terms of the NCAA recommendation, I don't think anybody

agrees with screening the athletes for the [sickle cell] trait. We are obviously afraid this would lead to discrimination and then this would obviously leave a lot of potentially very bright athletes out of competition, so this would lead to discrimination against sickle cell individuals.

He continued by offering an alternative to universal SCT screening in athletes,

The best way around this is [that] it has been shown in a number of studies that if you change the conditions of training in military and in athletics and give them [athletes] sufficient breaks and you hydrate them, you do prevent these sudden deaths. So, a better way of preventing this would be to apply these recommendations universally to everybody and that way you would not need to screen them for sickle cell trait which is something that could easily lead to discrimination.

When asked if he thought that the NCAA came to the decision to make this recommendation too quickly he stated,

I think that what they did was because of their fear of litigation. They wanted to put the burden on somebody else. They didn't want responsibility in it and it came up as a recommendation...

He believed that athletes, especially African Americans would eventually be treated unfairly as a result of this recommendation. When asked about the possibility of unfair treatment, he replied,

Yes, yes that's what we think might happen. If the NCAA is screening, especially African American athletes, for sickle trait...when they turn out to have SCT

obviously people will be afraid to include them in athletics and this might lead to their elimination. Whereas any risks that they may have because of sickle trait could easily be remedied by applying some precautions and there won't be any need for screening then.

The hematologist then commented on the dangers of genetics screening,

If you screen people for genetic diseases, the general screening doctrine goes that you shouldn't do screening if you don't have any means of either treating or preventing complications. So that applies here and in this case the fear is that the application of the NCAA's recommendation for screening of athletes may lead to discrimination or elimination of the athletes with sickle cell trait from athletics. The means are there to prevent complications from sickle cell trait so I think an alternative or better way [to combat this problem] would be to promote these universal precautions, not to screen everybody because they [universal precautions] have been shown to work. But if you are more concerned about the legal implications which is what the NCAA recommendation is based on everybody suspects [then you will screen everyone].

When asked about what should be included in a sickle cell trait education program, the hematologist recommended the following,

the basic facts [about sickle cell trait] and the number [thing people should know is that] sickle cell trait is not a disease but they [sickle cell trait carriers] can develop some complications when they are subjected to extremes like military training in the heat or extreme vigorous athletic training. But these can be



prevented with adequate measures such as giving them [athletes with sickle cell trait] enough breaks, not pushing them beyond tolerance and giving them sufficient hydration.

Each of the hematologist's comments can be summarized into two themes. 1) The sickle cell community believes that the NCAA recommendation may lead to discrimination against athletes who are SCT carriers, and 2) Applying the universal precautions of adequate hydration and sufficient rest to all athletes during training will eliminate the need for universal screening of athletes for SCT.

#### Chapter Summary

Overall, data analysis revealed that athletes and coaches lacked knowledge of sickle cell trait and they did not believe that NCAA mandated testing would be associated with discrimination towards SCT carriers in the future. Athletes desired health information and recognized the need to know SCT status. However, they were conflicted over whether or not they should tell their coaches. Coaches were aware and supportive of athlete health. However, that was not always portrayed to the athlete. The following chapter will integrate the quantitative and qualitative data during a critical discussion of the findings of the study.

## CHAPTER 6

### DISCUSSION, CONCLUSIONS, AND IMPLICATIONS

#### Introduction

The purpose of this mixed methods study was threefold. It was necessary to 1) determine perceptions of SCT and NCAA mandated SCT testing from college coaches and athletes' points of view; 2) determine the necessary components of the Sickle Cell Orientation and Education (S.C.OR.E) intervention that will be developed to educate intercollegiate athletes, as well as their coaches, about sickle cell trait from pre-participation screening to sickle cell trait diagnosis, and 3) to highlight the potential implications of an NCAA policy that mandates SCT testing.

Although one of the aims of the study was to develop an education program, contemporary health promotion does not merely aim to educate individuals about healthy practices, but to change organizational behaviors, physical and social environments of communities, and to influence and develop policies that support health (United States Department of Health and Human Sciences, 2005).

During this study, it was important to understand intrapersonal (e.g. knowledge, perceptions) factors that influenced athlete and coach outlook on Sickle Cell Trait (SCT) and National Collegiate Athletic Association (NCAA) mandated SCT testing. However, the study aimed to frame recommendations for intervention not only based upon individuals, but an ecological perspective. The PRECEDE-PROCEED model of program planning offered a rigorous framework to discover multi-level components of an athlete-coach specific SCT intervention (see Table 18). "Individual behavior is the fundamental unit of group behavior; thus achieving

policy and institutional change first requires influencing [and understanding] individuals”

(United States Department of Health and Human Sciences, 2005, p.12). Therefore, the

discussion will begin with individual factors that should be considered when developing a SCT intervention.

Table 18

*Summary of PRECEDE-PROCEED Findings*

Social Assessment/ Situational Analysis	Epidemiological Assessment	Educational/Ecological Assessment	Intervention Alignment and Administrative/ Policy Assessment
<p>Athletes are apathetic about pre-participation sports physicals</p> <p>Athletes’ desire health education/feedback</p> <p>Athletes’ have internal conflict between sharing health information and loss of playing time</p> <p>There is a need to examine the coach-athlete-athletic trainer dynamic</p> <p>Coaches support mandatory sickle cell trait testing for athletes</p> <p>Coaches support sickle cell trait carriers</p> <p>Coaches are concerned about their athletes’ health confidentiality issues</p>	<p>Athletes with SCT are susceptible to exertional rhabdomyolysis</p>	<p>Knowledge of SCT is associated with athlete outlook on SCT testing</p> <p>Perceived importance of knowing s/he has SCT is associated with athlete outlook on SCT testing</p> <p>Perception that NCAA 3c might result in athletes with SCT being treated unfairly is associated with athletes’ outlooks on NCAA 3c</p> <p>Athletes’ perceptions of receiving less playing time if he/she was diagnosed with SCT is associated with outlook on NCAA 3c</p> <p>Perceived risk of having SCT differs among ethnic groups</p> <p>Athletes have inadequate knowledge of SCT</p> <p>Athletes have inadequate knowledge of NCAA 3c</p> <p>Athletes have negative perceptions of SCT</p> <p>Athletes have positive perceptions of NCAA 3c</p> <p>There is racism in athletics</p> <ul style="list-style-type: none"> <li>• Caucasians perceive reverse discrimination</li> <li>• African Americans perceived athleticism is a “protective factor”</li> </ul> <p>Coaches have inadequate knowledge of sickle cell trait</p>	<p>Timing is critical</p> <p>Education should be Interactive (adult learner)</p> <p>Education should be athlete-specific</p> <p>Education should be mandated by the NCAA for coaches and athletic trainers</p> <p>NCAA Division 1 Proposal-2009-75-B has potential implications for discrimination towards SCT carriers</p> <p>Policy has not been made that protects athletes from possible negative implications</p> <p>Universal precautions are necessary to avoid discrimination</p> <p>A surveillance system is necessary to ensure protection of the athlete with SCT</p>

## Individual Factors

### *Knowledge of Sickle Cell Trait*

Controversy surrounds the NCAA's decision to mandate SCT testing among athletes. Much of this controversy came from the sickle cell community's knowledge of the history of genetic testing and discrimination that was specific to a positive diagnosis of SCT/SCD. In general, athletes and coaches in this study lacked knowledge of SCT and its negative history. The majority of athletes correctly answered survey questions relating to knowledge of SCT. However, qualitative focus groups and in-depth interviews revealed that both coaches and athletes had misconceptions about SCT and were unable to voice specifics (e.g., history of discrimination, genetic patterns, and clinical manifestations in athletes) of SCT. Ogamdi (1994) also found that college students lacked knowledge of SCD/SCT and incorrectly believed that SCT can change into SCD as did the participants in this study. The lack of knowledge of SCT resulted in a positive outlook about SCT testing among all the athletes who participated in the focus groups as well as the coaches. College athletes and coaches are accustomed to abiding by NCAA mandates. Therefore, they viewed SCT testing as another thing that they had to do in order to continue play of their chosen sport and were not initially bothered by the NCAA's mandate of SCT testing.

Examining factors based upon race/ethnicity is an important aspect of Critical Race Theory. Because sickle cell disease/trait primarily affects African Americans, this study was designed to not only determine factors that influence athletes' outlook on SCT, but to determine if there were differences between those factors among African Americans and Caucasians. All athletes had limited knowledge as well as serious misconceptions of SCT. SCT

and/or testing are not commonly discussed in the context of college athletics. Therefore, few of the study participants had previous exposure to information about the disease, regardless of race/ethnicity. Similarly, coaches knew only basic SCT information as it related to athletes being “winded” or “tired.”

#### *Perceived Susceptibility to Sickle Cell Trait*

Lack of knowledge may explain why a majority of athletes did not believe that they were at risk for SCT. Similarly, Gustafson (2006) found that perceived susceptibility among study participants was low because they believed that sickle cell did not run in their families. Athletes’ lack of perceived perceptibility may have implications on pre-participation screening of athletes. Athletes should be made aware that people of all ethnicities are susceptible to SCT and given adequate information to make an informed decision about testing. It is also important to note this finding because SCT diagnosis may cause elevated emotional distress to an athlete who does not believe that he/she is susceptible to SCT compared to the athlete who believes he/she is at risk for having SCT. The study also revealed that African Americans perceived that they were susceptible to SCT more so than Caucasians. African Americans may suffer more emotional distress during pre-participation screening than Caucasians because, in general, they may feel that they are at increased risk of SCT because, in the United States, it primarily affects African Americans. Perceived susceptibility to SCT should be considered both at pre-participation screening as well as when relaying a positive SCT result to an unsuspecting athlete. If a positive test is revealed, subsequent testing should be done also to confirm the diagnosis and eliminate the possibility of false positives.

### *Perceived Importance of Knowing S/he has Sickle Cell Trait*

Although the majority of athletes did not perceive that they were at risk for SCT, they still thought that it was important for an athlete to know if s/he had SCT. NCAA Division I proposal 2009-75-B allows athletes to sign a waiver if they do not want to be tested for SCT. However, if athletes are not knowledgeable about SCT or do not feel that they are susceptible, then the decision whether or not to test is likely made based upon their previous sports physical testing routine, apathy, or fear.

The fear of loss of playing time was a concern shared by athletes regardless of race/ethnicity. Division 1-A athletes are competitive, therefore, anything that might threaten playing time was purposefully avoided by the athletes. Athletes feared loss of playing time, however, for any health issue. In the study, the fear of lost playing time to sickle cell trait was secondary to the fear of injury. A prior finding indicated that athletes did not perceive that they were at risk for SCT. Therefore, discussion about lost playing time did not center around SCT, but on the fear that less than optimal health in general would cause decreased playing time. An important finding of the study was that athletes had cognitive dissonance concerning the transfer of health information to their coaches because they feared loss of playing time.

There are major implications for this finding. Athletes' fear of lost playing time resulted in concealing health information not only from coaches, but from athletic trainers. This may have major ramifications on the athletes' current and future health. This result highlights the need for trust within the athlete-coach-athletic trainer relationship. Limited SCT knowledge has potential implications for college athletes with SCT in the future. Whereas previous studies have shown how an individual's personal lack of knowledge may affect his/her reproductive

decision making (Asgharian & Anie, 2003), the current study illuminates how lack of knowledge among the athlete and “powerful others” such as coaches and athletic trainers may affect the future of the athlete who is a SCT carrier as well.

Lack of knowledge about SCT may induce fear for an athlete’s health and lead coaches or athletic trainers to remove an athlete from play too quickly. This reactive decision may limit or completely eliminate some athletes with SCT from Division I athletics. It is important to educate athletes about SCT. However, more importantly, coaches and athletic trainers should be educated to initiate awareness of perceived or real social injustices (e.g., discrimination, unequal treatment) that may result from the NCAA mandating SCT testing.

#### *Lack of Knowledge and Informed-Decision Making*

Lack of knowledge is a barrier to informed-decision making concerning SCT testing (Asgharian & Anie, 2003). If genetic testing is necessary to determine a college athlete’s SCT status, then the topic of informed decision making is central to this issue. Asgharian & Anie (2003) examined views of 35 female carriers of SCT. It was found that not every participant had clear understanding of what their SCT status actually meant. The study also found that obstacles to informed decision making included 1) inadequate knowledge of SCD/SCT, 2) Concern about what others may think if the subject of SCT was raised, and 3) Number of complications expected when facing the issue directly. Each of these is an obstacle to informed decision making for athletes as well. Athletes in the study had inadequate knowledge of SCT. There is a concern about what coaches may think if the athlete is diagnosed with SCT, and there may be a number of issues (e.g., discrimination, lost playing time) that athletes may face when

dealing with SCT directly. The NCAA must support athletes and their parents in making informed decisions and understanding the implications of SCT testing.

Lessons learned from HIV testing can offer insight into best practices for informed decision making in athletics. The Centers for Disease Control and Prevention (2006) recommends that informed consent for HIV include risks and benefits of testing, implications of the HIV test result, how the test will be communicated, and an opportunity to ask questions. Each of these is a necessary in athletics to ensure that an informed decision to test for SCT is made by an athlete.

#### *Knowledge of NCAA Guideline 3c*

Athletes were also unaware of NCAA Sports Medicine Guideline 3c: *Sickle Cell Trait and the Athlete*. This was expected by the researcher since athletes are not typically the individuals who read NCAA sports medicine guidelines; they are governed by them. The guidelines are read and interpreted by athletic trainers. Therefore, knowledge of an NCAA guideline had no affect on their opinions towards compliance with the guideline. Athletes will comply because they want to play. Therefore, knowledge of NCAA guideline 3c was not a factor that affected athletes' outlooks on SCT testing.

Although athletes were not expected to be aware of NCAA guidelines, this finding should not be dismissed as insignificant. Since athletes are not typically the ones who read NCAA sports medicine guidelines, it is of utmost importance that athletic trainers and coaches are well informed of the intricacies of the guidelines so that they can effectively relay them to the athletes. More importantly, governing bodies such as the NCAA have an obligation to consider the implications (i.e. discrimination) of guidelines and policies on the student athlete.



Hellman (2003) discusses the worry among scientists, physicians, genetics counselors, and their patients that genetic testing may cause discrimination. One of the major concerns of the sickle cell community is that NCAA SCT testing will cause unfair treatment and discrimination against athletes with SCT. One of the goals of this study was to highlight the perceptions of coaches and athletes concerning this issue.

The results of quantitative inquiry revealed that athletes were unsure if NCAA 3c would result in unfair treatment of athletes with SCT. However, qualitative inquiry revealed that neither athletes nor coaches believed that unfair treatment would occur. Therefore, they have positive outlooks on mandatory SCT testing and do not equate it with possible discrimination.

Coaches and athletes have not taken the time to contemplate the implications of SCT testing on an athlete. At this level (coach or athlete), coaches want to win and athletes want to play. Therefore, governing bodies (e.g. National Athletic Trainer's Association, NCAA) must consider the consequences of mass genetic testing because in essence, coaches and athletes are focused on the game and give little thought to the construction of policy.

Knowledge and perceptions of sickle cell trait and their relation to informed decision making are individual factors that must be considered when developing a sickle cell trait intervention for athletes and coaches. Beyond individual factors, there is a need to examine the culture of athletics to determine if it fosters an environment of trust or a "win at all costs" relationship between athletes and coaches. Schroeder (2010) suggests that "changing culture" is a common theme for both leaders and critics of intercollegiate athletics.

### Organizational Factors

Athletes want health education and feedback. Athletes have a basic understanding of the typical screening tests (e.g. concussion, eyesight) that occur during sports physicals. Therefore, it is not necessary to educate them on each individual test. However, with genetics testing such as SCT testing, athletes were unaware of the reason for testing as well as the implications of a positive SCT test result. In this case, they wanted to understand what they were being tested for as well as the implications it had for their careers as collegiate athletes.

Optimally, athletes should be given information and education about every test they have at a pre-participation sports physical. Subsequently, they would want to receive and understand the results of each of these tests. Realistically, the pre-participation sports physical will continue to be a process that must happen quickly in order for play to begin, and many of the athletes will not be concerned with the results. A discussion about changes in the pre-participation sports physical process warrants a dialogue about change in the organizational structure of athletics.

The pre-participation sports physical process should be consistently examined for its thoroughness and effectiveness. Athletes need to have the opportunity to view the results of their own physicals. Most importantly, athletes need to feel that their medical needs are being cared for. The athletes in this study felt that their physicals were less thorough each year. Therefore, they had the perception that physicals were only taking place to prevent liability issues. Females were more concerned about their health and the results of the tests than males. It cannot be said that males are unconcerned about their health. Therefore, there is a

need to centralize the information so that athletes can access at least their basic health information.

#### *Athletes' Cognitive Dissonance About Sharing Health Information*

Coaches may be supportive of the health of their athletes. However, this may not necessarily be what they portray or what the athletes perceive. Coaches are under tremendous pressure to win games to maintain employment; and athletes are under pressure to perform to stay on the team. The athletes are not oblivious of this. Therefore, the desire to win may inadvertently overshadow the concern for the athlete's health.

Schroeder (2010) suggests that externalities such as funding sources, television networks, and governing bodies such as the NCAA often influence the culture within an athletic organization. Schools garner financial support through outside sources and these sources are most likely to support schools with winning teams. Therefore, athletes are a large part of the business. They are not treated as employees, yet provide a majority of the product.

The finding that athletes are reluctant to reveal health information to coaches is one of great importance. It is imperative that coaches guard against treating athletes as commodities and consciously relay their concern for the athletes' health. Though this study was not designed to examine the culture of athletics and broad conclusions cannot be made based upon the minimal data collected, this finding cannot be ignored and must be explored in future studies.

#### *Uncertainty About who Makes Decisions Concerning Athlete Health*

Coaches are not medical professionals. The athletic trainers for the teams work in this capacity. Therefore, the coach-athlete-athletic trainer dynamic should be further explored. It

was not clear, from the athletes' perspectives, which had the final say in regards to their health. Athletes seemed to be caught between the coaches' desire to win and the athletic trainers' desire to keep them healthy. Athletes want to both be healthy and they want to win games.

The researcher did not assume that coaches lacked the desire for their athletes to be healthy. The current study refutes that assumption. It is also not assumed that athletic trainers do not want the team to win. Although the roles of the coaches, athletic trainers, and athletes are different, the health of the athlete should be each constituent's ultimate goal.

#### *Uncertainty of Whether or Not the Athletes' Health Information is Confidential*

Confidentiality of health information is essential, regardless of its genetic nature. Athletes in this study felt that all of their medical information should be held in confidence. Planting, Natowicz, Kass, Hull, Gosting and Fadon (2003) found similar results. In a study of the general public, participants did not view genetics information any differently than non-genetics information. Study participants felt that all medical information should be protected.

Athletic trainers and team doctors are often under contractual obligations and have to make the decision to honor the athlete's wishes to conceal health information or honor their contractual obligations. Anderson (2008) suggests that athletic trainers and team doctors should be supported in their ability to resist pressure from team coaches through a rigorous code of ethics. Findings of the current study suggest that athletes should be able to trust sensitive medical information to their trainers. The athlete-athletic trainer-coach distribution of health information should be further examined to determine gaps that exist as well as breeches of confidentiality that may occur. HIV testing has brought about policies that included pre/post test counseling, anonymous testing, and strict protections of confidentiality

(Lazzarini, 2001). It is essential that the NCAA outline policies that protect the privacy of athletes who test positive for SCT as well.

### *Racism and College Athletics*

Unintended discrimination towards SCT carriers, and subsequently African American athletes, is the primary implication of NCAA mandatory SCT testing that the sickle cell community aims to avoid. Therefore, the study integrated Critical Race Theory in every aspect from design to analysis. When the focus groups were designed, the researcher sought to determine if answers to questions would change when the groups were mixed. All answers remained the same except those describing race in athletics. Athletes recognized the inherent nature of racism in athletics. Caucasian athletes recognized that African American athletes were seen as stronger and faster. African Americans recognized this as well. Being African American was seen as a protective factor for some of the African American athletes. They felt that they were needed in their sport. They also believed that the athletic director and coaches knew that African Americans were a necessary component of a successful team. Therefore, African American athletes believed that African Americans would never be discriminated against (because of sickle cell trait) in college athletics because it is a business and coaches want to win. None of these concerns or opinions was voiced when the groups were mixed race.

African American athletes in the current study did not perceive that they were treated differently, on campus, than their white counterparts. They suggested that racism was a concept that has been obscure in the United States for many years. Tatum (1997) suggests that this is often a misconception of college students. Harper (2005) found results contrary to the

current study determining that African American athletes felt they were treated differently on campus and in athletics and also felt that they had less opportunity to rise to leadership positions within athletics.

In this study, African American and Caucasian athletes did, however, recognize racism within college athletics. What the African American participants described was interest convergence, a tenet of Critical Race Theory. They proudly expressed that the athletic director and coaches would ensure that African Americans would play regardless of SCT status because they want to win. They equated the presence of African Americans on the team with a team's success.

African American athletes are often glorified in sport. Brooks (2008) debates that African Americans have become preferred workers. Therefore, they are not necessarily more talented, but have been given more opportunities because it benefited capitalist interests and because of African American's marginalized position in society.

This finding is important because it further illuminates the issue of athletics culture. It is positive that African American athletes feel protected in college athletics. However, in this unique instance, the lack of 'blackness' may prove to be detrimental to the career of the Caucasian athlete. The Caucasian athlete should not suffer social injustice because of the inherent nature of racism in sport.

### Policy

Discrimination towards the athlete with SCT is a major concern for the sickle cell community. The NCAA has developed policy that mandates SCT screening. However, implementation was premature because the policy lacked subsequent sections regarding post-

diagnosis protection of the athlete with SCT. To avoid possible discrimination, the NCAA should consider universal precautions for all athletes instead of testing all athletes for SCT. The United States military has a long history of controversy (Scott, 1982; Gunby, 1984; Voge, Rosado, & Contiguglia, 1991) related to sickle cell trait from which the NCAA can learn. The stories of the United States military and the NCAA have notable parallels as they relate to sickle cell trait and policy development.

In 1973, the U.S. Military adopted policy that required that all candidates for the military be screened for sickle cell trait. Those found to have sickle cell disease were excluded from military service, and those who had SCT were excluded from aviation duties (Diggs, 1984). The restriction of SCT carriers from duty within the United States Air Force brought about controversy and lawsuits against this branch of the military in 1979. In 1973, Dr. Robert F. Murray, Jr. determined that there was “no reason to exclude trait carriers from flight duty except for pilots and co pilots” (Scott, 1982, p. 835). In 1981, the Department of Defense, in a memo to the secretaries of the Army, Navy, and Air Force, ordered that them to “revise your physical standards to eliminate any occupational or academy standards that restrict individuals with SCT” (Department of Defense Memo, 1981). It further stated that, “We must develop additional scientific information about sickle cell trait in the military. Accordingly, the Assistant Secretary of Defense is directing the Uniformed Services University of the Health Sciences to develop and perform a monitoring study” (Department of Defense Memo, 1981). After continued monitoring of the issue of SCT and military service, another memo was sent to the Secretaries of Military Departments in 1996 (Edwin Dorn, Department of Defense memo, November, 22, 1996). It stated,

After considering recommendations from the Armed Forces Epidemiological Board and Service data regarding sickle cell related mortality, I have decided that Hemoglobin S testing for SCT **should not** be mandated for military accessions. Medical history screening guidelines at accession appear to be able to successfully exclude entry into the military of most individuals with sickle cell disease, and this screening shall be continued. Available data on individuals with SCT indicate that most related sudden deaths can be prevented by adequate preventive measures [universal precautions] against heat related illness. The cost of screening for a risk factor which rarely, if ever, will result in death under normal circumstances appears to outweigh the benefit of conducting the screening program. Preventive measures [universal precautions] against health related illness, such as adequate hydration, heat illness awareness programs and careful monitoring of basic trainees must be continued and improved.

[emphasis added]

The fact that the history of the United States Military as it relates to sickle cell trait policy is so similar to that of the NCAA thirty years later is alarming and brings credibility to those who believe that NCAA mandated testing was a legal maneuver more so than a protective one for athletes. Information about SCT and the possible implications of extreme exertion and heat related illness is not new information. This information has been studied for decades (Scott, 1982; Diggs, 1984). Therefore, it is imperative that the NCAA thoroughly review the history that the military has etched with the issue of SCT and not repeat it. Universal precautions are necessary to avoid discrimination towards SCT carriers and to protect not only



athletes with SCT, but all athletes who perform under extreme (i.e. heat, cold, altitude) conditions.

It is also vital that the NCAA develop a surveillance system to determine the effects of mandatory SCT testing on athletes, their families, coaches, and universities to ensure that unintended harm is avoided. This system should focus on the epidemiology of SCT and athletics. Most importantly if screening continues to be mandated, the surveillance system must include an assessment of the social aspects of SCT and athletics from the SCT carrier's (i.e., athlete) point of view. Coaches and athletic trainers must be mandated to obtain education not only about the basics of sickle cell disease, but the history of discrimination of the disease and trait. Then they must be monitored to ensure that they are compliant with education standards and to ensure that athletes are not being discriminated against.

The researcher would suggest a task force at each NCAA member university that consists of at minimum the head athletic trainer, the athletic director, a physician, coaches (2-3), and a student representative (athlete) who is a sickle cell trait carrier. The NCAA should develop a questionnaire that this task force must complete each year to be sent to the NCAA for monitoring purposes. The NCAA should also develop a task force to oversee the individual member school groups so that accountability is further established.

#### Limitations of the Study

There are several limitations to the study. The sample size was small, therefore, quantitative analysis was limited and the results can only be generalized to this particular group of athletes at the point of data collection. Small samples, however, allowed the researcher to

obtain detailed accounts from participants and to gain deeper understanding of their perspectives on NCAA mandated testing.

The small sample size of the study limited quantitative analysis. Cross tabulations yielded zero cell counts which made it impossible to determine odds ratios. Low cell counts also limited further statistical analysis outside of the determination of associations. Because the “neutral” answer dominated some questions, it was necessary that they were not eliminated from data analysis. This meant that there were two-by-three tables versus two-by-two tables. Therefore, the Fischer’s Exact statistic could not be utilized to determine significance. These limitations illustrate the need to conduct the study on a larger scale.

The survey was designed so that “true” answers could easily be guessed if the athletes just marked answers down the page. The mixed methods design of the study was a strength and offset the weakness of the survey design. Qualitative data provided insight into athlete and coach knowledge and therefore filled in any gaps that were identified from the quantitative phase of the study. In phase II of the study, focus group three did not consist of any white males. Therefore, focus group three findings do not contain the perspectives of a Caucasian male athlete.

Although the study has these limitations, it is a starting point for future studies and deeper discussion by athletic governing bodies concerning mandated SCT screening. This study is the first to gather the perspectives of athletes and coaches concerning this issue. Therefore, the themes that emerged from this pilot study can be utilized as a spark to initiate deeper, more critical discussion surrounding NCAA mandated SCT testing.

## Summary of Recommendations for Intervention

### *Timing of Intervention is Critical*

Both athletes and coaches expressed that the period within the two weeks before fall semester begins is the most effective time to have a health education session/intervention. This is the time when athletes have returned to school but have not yet started classes. Athletes and coaches are extremely busy after the school year begins. Therefore, it would be almost impossible to find time to meet with them after that two week time period. It was also found that the structure of the program is as critical as is timing.

### *Interactive, Athlete-Specific*

Coaches and athletes agreed that health education should be interactive so that it would peak the athletes' interest as well as optimize recall of the information. They also expressed the need for it to be athlete-specific. General practitioners or nutritionists are not as in tune to the needs of athletes who exercise for multiple hours per day and consequently whose bodies are in peak condition. Therefore, coaches and athletes recognized the need to receive health information from someone who works specifically with athletes. The ideal individual to provide the training was most often identified as athletic trainers.

### *Components of a SCT Education/Intervention Program*

This study was designed to determine the necessary components of an education program designed to educate coaches and athletes from pre-participation screening to possible sickle cell trait diagnosis. This section will highlight the necessary components of an educational curriculum.

### *Individual Level Components*

#### *Pre-Screening.*

Athletes should be informed about the specifics of SCT testing before taking the screening test. A prescreening counseling handout or some other form of information should be given so that athletes can make an informed decision about whether or not they want to participate in SCT testing. Currently, athletes can sign a waiver to opt out of testing. However, sufficient information should be given to an athlete prior to making the decision to participate in or decline testing. Following the suggestions of coaches and athletes, the information should also be athlete-specific. Recommendations for information in the handout include: Basic sickle cell trait knowledge information such as: 1) SCT is not a disease; 2) People are born with SCT; 3) SCT primarily affects African Americans, but any person of any ethnicity can have sickle cell disease; 4) Rationale for SCT testing among athletes; and 5) Implications of a positive SCT test on the collegiate athlete's career.

#### *Sickle Cell Trait Diagnosis.*

Upon SCT diagnosis, athletes and coaches need a deeper understanding of SCT as well as the implications it can have for the athlete. An understanding of the history of SCT and discrimination is also important for coaches so that they are made aware of possible biases they may have as a result of an athlete's diagnosis with SCT. Upon diagnosis with SCT coaches and athletes should receive:

- More in-depth SCT knowledge which will include: 1) A brief history of SCT and its history of discrimination; 2) An understanding that SCT is not a disease; 3) An understanding of the inheritance pattern of SCT and the implications that it has

on marriage and future childbearing; 4) Information concerning the implications for the athlete with SCT; 5) Information about what the coaches and athletes should expect at games and practice.

- Communication strategies

Communication strategies would include: 1) signals that the athlete can give coaches or athletic trainers when they do not feel well; and 2) Signals that coaches and athletic trainers can give athletes when they sense something is wrong.

- Counseling

- Athletes should be offered counseling concerning a SCT diagnosis since this information can be potentially devastating. Counseling options should also be available. Genetics and psychological counseling can be essential to properly handling a SCT diagnosis.
- Families should also be offered counseling resources; as a positive genetics test for an athlete offers information into parental genetics as well. This may raise questions of paternity. Therefore, counseling resources should be made available to support not only the athlete, but the athletes' family.

### *Organizational Level Components*

There is a need to examine the culture of athletics. It is vital that the NCAA and its member universities:

- Revise the pre-participation screening process to include education for athletes

- Develop a culture of trust between athlete and coach
- Ensure athlete health information confidentiality
- Develop the coach-athletic trainer relationship
- Recognize 1) the sickle cell community's primary concern of the possibility of discrimination towards the sickle cell trait carrier; and 2) the inherent nature of racism in athletics and take steps toward cultural competence and the elimination of social injustices that may result from an athlete's possession of SCT

#### *Policy Level Components*

- Develop universal precautions for all athletes to eliminate the need for SCT testing
- Develop policy mandating SCT task forces at each member University to monitor SCT and its relation to athletes
- Develop a surveillance system to assist in the elimination of social injustices toward athletes who possess the sickle cell trait. This system should not only include epidemiological analysis, but also an analysis of the implications (social, behavioral, etc.) for the athlete with SCT.

#### Summary and Conclusions

The purposes of this study were to 1) determine perceptions of SCT and NCAA mandated SCT testing from college coaches and athletes' points of view; 2) determine the necessary components of the Sickle Cell Orientation and Education (S.C.OR.E) intervention that will be developed to educate intercollegiate athletes, as well as their coaches, about sickle cell

trait from pre-participation screening to sickle cell trait diagnosis, and 3) to highlight the potential implications of an NCAA policy that mandates SCT testing.

To answer the research questions and fulfill the purpose of the current study, it was necessary to employ a mixed methods design with under the umbrella of multiple theories. Quantitative and qualitative inquiries were guided by Critical Race Theory and the Health Belief Model. Quantitative inquiry left gaps that the qualitative inquiry was able to fill. Critical Race Theory and the Health Belief Model proved to be an effective combination of theory to answer the research questions and fulfill the purpose of the study. Race was examined for each of the hypotheses in phase I (quantitative) and throughout the focus group discussions in phase II (qualitative). The beliefs and perspectives of athletes were also examined quantitatively in phase I and qualitatively in phase II.

It was found that knowledge, perceived importance of an athlete knowing his/her SCT status, perception of NCAA 3c resulting in unfair treatment of athletes, perception of receiving less playing time, and perception of risk of having SCT were all associated with athletes' outlooks on SCT and NCAA 3c. Therefore, each of these should be considered when discussing SCT with an athlete whether it is prior to a pre-participation sports physical or after an athlete is diagnosed with SCT.

Issues outside the scope of the study surfaced and therefore deserve consideration. Athletes' concern for lost playing time affected their level of trust in coaches and athletic trainers. This also brought about the issue of confidentiality and protection of athlete health information. It was determined that racism was inherent in college athletics and should be

addressed so that Caucasian athletes do not suffer social injustices as a result of their lack of 'blackness'.

Overall, athletes and coaches did not perceive that athletes with SCT would be discriminated against. This may have been due to their lack of knowledge of SCT or the newness of NCAA mandated SCT testing or structural policies that covertly perpetuate inequity. It was determined that lack of knowledge of SCT is a major predictor of athlete outlook on SCT. Therefore, it is important that athletes and coaches are educated about SCT to prevent discrimination or elimination of athletes from play in the future.

#### Recommendations for Policy and Practice

As was recommended by the hematologist who participated in the study, NCAA policy makers should implement universal precautions for all athletes as opposed to performing universal SCT testing to determine which athletes have the SCT. This would be beneficial to all athletes and prevent possible discrimination towards or elimination of athletes with SCT. Because of the history of SCT and genetics testing in general, it is necessary to examine genetics screening practices in athletics. Schroeder (2010) states that the environment of intercollegiate athletics can force leaders to make decisions rapidly and without all desired background information. Mandating SCT testing as a result of litigation often leads to failure to consider the social and behavioral aspects of policy. It is necessary for the NCAA to re-think the cognitive and emotional effects of SCT testing on the athlete as well as family members. Resources must be put in place to educate as well as counsel individuals affected by SCT.

The NCAA should mandate training for coaches; and athletic trainers must take it upon themselves to become educated about SCT so that they do not initiate discrimination by pulling



athletes from play based upon unfounded fears. Athletic trainers must educate coaches and be the bridge between policy interpretation and implementation.

#### Recommendations for Future Research

Recommendations for future research are as follows: 1) Studies of the perspectives of coaches and athletes should be conducted at other colleges and universities to determine further recommendations for a SCT intervention. Context varies across school and location within the country. Therefore, it is important to determine recommendations from other schools as well; 2) The knowledge and perspectives of athletic trainers should be examined because they are the individuals who interpret NCAA policy and educate coaches and athletes concerning their specifications; 3) It is important to determine the perspectives of athletes who have been diagnosed with SCT. Information from these athletes' perspectives can be incorporated to further refine a SCT intervention; and 4) Scientists and physicians should continue to study the association of SCT with sudden deaths during extreme exertion.

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APPENDIX A  
LIST OF ABBREVIATIONS

AA	African American
AS	The genotype that describes sickle cell trait
CAP	College of American Pathologists
CF	Cystic Fibrosis
CRT	Critical Race Theory
Hb	Hemoglobin
HBM	Health Belief Model
HIV	Human Immunodeficiency Virus
IRB	Institutional Review Board
NATA	National Athletic Trainer's Association
NCAA	National Collegiate Athletic Association
PRE-PRO	PRECEDE-PROCEED
RBC	Red Blood Cells
S.C.OR.E.	Sickle Cell Orientation and Education
SCD	Sickle Cell Disease
SCT	Sickle Cell Trait
SS	The genotype that describes sickle cell disease
TSD	Tay Sachs Disease

## APPENDIX B

## GLOSSARY OF TERMS

*Carrier testing* is a type of genetic testing used to determine whether an individual carries one copy of an altered gene for a particular recessive condition. Carrier testing is done because of a family history of a genetic disorder or because of racial or ethnic background.

*Concurrent Triangulation Mixed Methods* is an approach to data collection where the researcher collects both quantitative and qualitative data, concurrently to see if there is convergence, differences, or some combination (Creswell, 2009).

*Critical Race Theory* is a conceptual lens used to examine racism, racial disadvantages, and inequitable distribution of power and privilege within institutions and society (Bell, 1987; Delgado & Stefancic, 2001).

*Cystic fibrosis (CF)* is an autosomal recessive disorder characterized by chronic lung disease and pancreatic insufficiency and is the most common genetic disorder among the U.S. Caucasian population.

*Exertional Rhabdomyolysis* is the rapid breakdown of muscles starved of blood after extreme exertion.

*Genetic testing* is the laboratory analysis of DNA, RNA, or chromosomes. Genetic testing is done to predict risk of disease, screen newborns for disease, identify carriers of genetic disease, and establish prenatal or clinical diagnosis or prognosis, as well as to direct clinical care.

*Health Belief Model (HBM)* is a theory developed in the 1950s in an attempt to explain the failure of people to participate in preventative health behaviors such as screening and immunization programs. The theory was developed by Rosenstock, Hochbaum, and Leventhal (Rosenstock, 1974)

*Hemoglobin (Hb)* is the oxygen carrying component of the blood.

*Hypernatremia* is a greater than normal concentration of sodium in the blood. Sodium is an electrolyte that helps with nerve and muscle function, and also helps to maintain blood pressure.

## APPENDIX B, CONTINUED

## GLOSSARY OF TERMS

*Intercollegiate* is a term used to describe college sports/teams that compete against other college sports/teams.

*National Collegiate Association 3C* in this study is synonymous with NCAA recommended/mandatory sickle cell trait testing.

*PRECEDE-PROCEED* is an approach to program planning that consists of eight phases: social assessment, epidemiological assessment, educational and ecological assessment, administrative and policy assessment and intervention alignment, implementation, process evaluation, impact evaluation, and outcome evaluation.

*Pre-Participation Exam* is the medical exam that athletes are required to go through prior to participation in an organized sport.

*Sickle cell disease (SCD)* is an inherited blood disorder in which the red blood cells are shaped like a sickle as a result of a predominance of hemoglobin. The disease is most commonly found in African Americans in the United States.

*Sickle cell trait (SCT)* is an inherited condition in which both Hemoglobin A and Hemoglobin S are produced in the red blood cells. SCT is a carrier state and not a disease.

*Tay-Sachs disease (TSD)* is an autosomal recessive disorder of the central nervous system in which symptoms develop within the first 6 months of life and end fatally 3 to 4 years later. Apparently normal at birth, most children with TSD show signs of neurological deterioration sometime in their first year of life. TSD is most common in individuals of Ashkenazi Jewish ancestry.

## APPENDIX C

## INSTITUTIONAL REVIEW BOARD APPROVAL FORMS

Georgia Southern University Office of Research Services & Sponsored Programs		
<b>Institutional Review Board (IRB)</b>		
Phone: 912-478-0843		Veazey Hall 2021
		P.O. Box 8005
Fax: 912-478-0719	IRB@GeorgiaSouthern.edu	Statesboro, GA 30460

**To:** Raymona H. Lawrence  
P.O. Box 8078  
Statesboro, GA 30460

**CC:** Charles E. Patterson  
Associate Vice President for Research

**From:** Office of Research Services and Sponsored Programs  
Administrative Support Office for Research Oversight Committees  
(IACUC/IBC/IRB)

**Date:** April 5, 2010

**Subject:** Status of Application for Approval to Utilize Human Subjects in Research

After a review of your proposed research project numbered H10306 and titled "Development of the Sicldle Cell Orientation and Education (S.C.O.R.E.) Program for the Collegiate Athlete: A Response to NCAA Guideline 3c", it appears that (1) the research subjects are at minimal risk, (2) appropriate safeguards are planned, and (3) the research activities involve only procedures which are allowable. You are authorized to enroll up to 370 subjects.

*Therefore, as authorized in the Federal Policy for the Protection of Human Subjects, I am pleased to notify you that the Institutional Review Board has approved your proposed research.*

**This IRB approval is in effect for one year from the date of this letter.** If at the end of that time, there have been no changes to the research protocol; you may request an extension of the approval period for an additional year. In the interim, please provide the IRB with any information concerning any significant adverse event, **whether or not it is believed to be related to the study**, within five working days of the event. In addition, if a change or modification of the approved methodology becomes necessary, you must notify the IRB Coordinator prior to initiating any such changes or modifications. At that time, an amended application for IRB approval may be submitted. Upon completion of your data collection, you are required to complete a *Research Study Termination* form to notify the IRB Coordinator, so your file may be closed.

Sincerely,

Eleanor Haynes  
Compliance Officer



## APPENDIX C, CONTINUED

## INSTITUTIONAL REVIEW BOARD APPROVAL FORMS

Georgia Southern University Office of Research Services & Sponsored Programs	
<b>Institutional Review Board (IRB)</b>	
Phone: 912-478-5465	Veazey Hall 2021 P. O. Box 8005 Statesboro, GA 30460-8005
Fax: 912-478-0719	IRB@GeorgiaSouthern.edu

**To:** Raymona H. Lawrence  
P.O. Box 8078  
Statesboro, GA 30460

**Cc:** Charles E. Patterson  
Vice President for Research and Dean of the Graduate College

**From:** Office of Research Services and Sponsored Programs  
Administrative Support Office for Research Oversight Committees  
(IACUC/IBC/IRB)

**Date:** June 2, 2010

**Subject:** Status of Research Study Modification Request

After a review of your Research Study Modification Request on research project numbered "**H10306**" and officially titled "**Development of the Sickle Cell Orientation and Education (S.C.O.R.E.) Program for the Collegiate Athlete: A Response to NCAA Guideline 3c.**" it appears that (1) the research subjects are at minimal risk, (2) appropriate safeguards are planned, and (3) the research activities involve only procedures which are allowable.

*Therefore, as authorized in the Federal Policy for the Protection of Human Subjects, I am pleased to notify you that the Institutional Review Board has approved your modification request to add a qualitative data collection phase, to add focus groups, to add in-depth interviews, to recruit athletes for the focus group, to recruit coaches, athletic trainers, and hematologists for in-depth interviews, to add data collection focus groups, to add data collection in-depth interviews, to begin data analysis, and to change the words "survey" and "athlete" to "discussion" and "coaches, athletic trainers, and hematologists respectively on your informed consent.*

The IRB approval is still in effect for one year from the date of your original application approval and will expire on April 5, 2011. If at the end of that time, there have been no further changes to the research protocol; you may request an extension of the approval period for an additional year. In the interim, please provide the IRB with any information concerning any significant adverse event, whether or not it is believed to be related to the study, within five working days of the event. In addition, another change or modification of the approved methodology becomes necessary; you must notify the IRB Coordinator prior to initiating any such changes or modifications. At that time, an amended application for IRB approval may be submitted. Upon completion of your data collection, you are required to complete a *Research Study Termination* form to notify the IRB Coordinator, so your file may be closed.

Sincerely,

Eleanor Haynes  
Compliance Officer

## APPENDIX D

## SICKLE CELL DISEASE CONTROL ACT

86 STAT.] PUBLIC LAW 92-294—MAY 16, 1972

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## FINDINGS AND DECLARATION OF PURPOSE

SEC. 2. (a) The Congress finds and declares—

(1) that sickle cell anemia is a debilitating, inheritable disease that afflicts approximately two million American citizens and has been largely neglected;

(2) that the disease is a deadly and tragic burden which is likely to strike one-fourth of the children born to parents who both bear the sickle cell trait;

(3) that efforts to prevent sickle cell anemia must be directed toward increased research in the cause and treatment of the disease, and the education, screening, and counseling of carriers of the sickle cell trait;

(4) that simple and inexpensive screening tests have been devised which will identify those who have the disease or carry the trait;

(5) that programs to control sickle cell anemia must be based entirely upon the voluntary cooperation of the individuals involved; and

(6) that the attainment of better methods of control, diagnosis, and treatment of sickle cell anemia deserves the highest priority.

(b) In order to preserve and protect the health and welfare of all citizens, it is the purpose of this Act to establish a national program for the diagnosis, control, and treatment of, and research in, sickle cell anemia.

## AMENDMENTS TO PUBLIC HEALTH SERVICE ACT

SEC. 3. (a) Section 1 of the Public Health Service Act is amended by striking out "titles I to X" and inserting in lieu thereof "titles I to XI".

79 Stat. 950  
84 Stat. 1506  
42 USC 201  
note.

(b) The Act of July 1, 1944 (58 Stat. 682), as amended, is amended by renumbering title XI (as in effect prior to the enactment of this Act) as title XII, and by renumbering sections 1101 through 1114 (as in effect prior to the enactment of this Act), and references thereto, as sections 1201 through 1214, respectively.

(c) The Public Health Service Act is further amended by adding after title X the following new title:

41 USC 300.

## "TITLE XI—SICKLE CELL ANEMIA PROGRAM

"SICKLE CELL ANEMIA SCREENING AND COUNSELING PROGRAMS AND INFORMATION AND EDUCATION PROGRAMS

"Sec. 1101. (a) (1) The Secretary may make grants to public and nonprofit private entities, and may enter into contracts with public and private entities, for projects for the establishment and operation of voluntary sickle cell anemia screening and counseling programs, primarily through other existing health programs.

"(2) The Secretary shall carry out a program to develop information and educational materials relating to sickle cell anemia and to disseminate such information and materials to persons providing health care and to the public generally. The Secretary may carry out such program through grants to public and nonprofit private entities or contracts with public and private entities and individuals.

"(3) In making any grant or contract under this title, the Secretary shall (1) take into account the number of persons to be served by the program supported by such grant or contract and the extent to which rapid and effective use will be made of funds under the grant or

## APPENDIX E

### INFORMED CONSENT: ATHLETES

#### **WHAT IS THE PROJECT ABOUT?**

The purpose of this research project is to:

Learn about athletes' knowledge, attitudes, and perceptions of an NCAA guideline.

Determine necessary components of an education program for athletes.

You are being asked to take part in the research project because you are an athlete, on an NCAA governed team at Georgia Southern University.

#### **WHAT WILL YOU BE ASKED TO DO?**

If you want to take part, you will be asked to:

Fill out a short survey

#### **WHAT WILL YOU GET OUT OF BEING IN THE PROJECT?**

Results from the surveys will be used to develop and determine a health education program for athletes

This will assist GSU in becoming a leader in athlete health education.

#### **ARE THERE RISKS TO TAKING PART?**

Taking part in this research study should not put you at risk. You can be sure that none of the information on the survey will be connected to you. It is confidential and will not be shared with anyone.

#### **ARE THERE COSTS TO TAKING PART?**

There are no costs to taking

part in the study other than the time to complete the survey.

#### **DO YOU HAVE TO TAKE PART?**

You do not have to be part of the study if you do not want to. Taking part in the study is up to you. You can stop taking part at any time. If you decide to stop, no one will be angry or upset with you.

#### **IS WHAT I SAY IN THE SURVEY PRIVATE?**

To protect your privacy, your name will not be included on the survey. This information will not be connected to you in any way. All data will be reported as a summary of information.

#### **WHO ARE THE PEOPLE RUNNING THIS STUDY? CAN I CALL THEM?**

The Principal Investigator for this research study is Raymona H. Lawrence, MPH, DrPHc. Her telephone number is (912) 478-

1034. She is a doctoral candidate in the Jiann Ping Hsu College of Public Health at Georgia Southern University. She is also the

University Wellness Program Director. Her address is PO Box 8078, Statesboro, GA 30460.

APPENDIX E, CONTINUED  
INFORMED CONSENT: ATHLETES

This study has been reviewed and approved by the Institutional Review Board at Georgia Southern University, a group that makes sure that study participants are treated fairly and protected from harm.

If you have questions about your rights as a study participant, or are not happy with any aspect of this study, contact -- anonymously, if you wish -- the

Office of Research and Sponsored Programs  
Georgia Southern University  
PO Box 8005  
Statesboro, GA 30460 or  
**Phone:** 912-478-5465  
**Fax:** 912-478-0719  
**E-mail:** [research@georgiasouthern.edu](mailto:research@georgiasouthern.edu)

**AGREEMENT STATEMENTS**

Do you have any questions about the research study?

YES                      NO

Do you agree to take part in the research study?

YES                      NO

If you sign your name below, it means that you agree to take part in the research study.

---

Signature of Athlete

---

Printed Name of Athlete

---

Date

## APPENDIX F

## INFORMED CONSENT: COACHES, ATHLETIC TRAINERS, HEMATOLOGIST

**WHAT IS THE PROJECT ABOUT?**

The purpose of this research project is to:

Learn about coaches', athletic trainers', and hematologists' knowledge, attitudes, and perceptions of an NCAA guideline.

Determine necessary components of an education program for athletes, coaches, and athletic trainers.

You are being asked to take part in the research project because you are a coach, athletic trainer, or hematologist, who has the potential to be affected by NCAA Guideline 3c.

**WHAT WILL YOU BE ASKED TO DO?**

If you want to take part, you will be asked to:

Participate in a 45min to 1 hour discussion about athlete, coach, and athletic trainer health education.

**WHAT WILL YOU GET OUT OF BEING IN THE PROJECT?**

Results from the interview will be used to develop and determine a health education program for athletes, coaches, and athletic trainers.

This will assist GSU in becoming a leader in athlete health education.

**ARE THERE RISKS TO TAKING PART?**

Taking part in this research study should not put you at risk. You can be sure that none of the information from the discussion will be connected to you. It is confidential and will not be shared with anyone.

**ARE THERE COSTS TO TAKING PART?**

There are no costs to taking part in the study other than the time to take part in the discussion.

**DO YOU HAVE TO TAKE PART?**

You do not have to be part of the study if you do not want to. Taking part in the study is up to you. You can stop taking part at any time. If you decide to stop, no one will be angry or upset with you.

**IS WHAT I SAY IN THE SURVEY PRIVATE?**

To protect your privacy, your name will not be included on the discussion notes. This information will not be connected to you in any way. All data will be reported as a summary of information.

## APPENDIX F, CONTINUED

## INFORMED CONSENT: COACHES, ATHLETIC TRAINERS, HEMATOLOGIST

**WHO ARE THE PEOPLE RUNNING THIS STUDY? CAN I CALL THEM?**

The Principal Investigator for this research study is Raymona H. Lawrence, MPH, DrPHc. Her telephone number is (912) 478-1034. She is a doctoral candidate in the Jiann Ping Hsu College of Public Health at Georgia Southern University. She is also the University Wellness Program Director. Her address is PO Box 8078, Statesboro, GA 30460.

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**Fax:** 912-478-0719  
**E-mail:** [research@georgiasouthern.edu](mailto:research@georgiasouthern.edu)

**AGREEMENT STATEMENTS**

Do you have any questions about the research study?

YES                      NO

Do you agree to take part in the research study?

YES                      NO

If you sign your name below, it means that you agree to take part in the research study.

---

Signature of Participant

---

Printed Name of Participant

---

Date

## APPENDIX G

## SICKLE CELL ORIENTATION AND EDUCATION (S.C.OR.E.) SURVEY

*Thank you for taking the time to participate in my survey. You were chosen to participate in this study because your insights are valuable and you are one of the few people on campus who are privileged to play on a team governed by the National Collegiate Athletics Association NCAA (NCAA). The survey is designed to learn about what you know about issues related to a new recommendation outlined by the NCAA. Your opinion really matters. Please take your time answering each question. The information you share will not be connected to you in any way. All information will be reported together and will not identify you individually.*

Term	Definition
Genetic Testing	Tests that identify genes that you inherit from your parents.

Please check the term that best describes you:

1. What is your gender?  Male  Female
2. What is your Race/Ethnicity? Please check one that best describes you.
  - American Indian or Alaska Native
  - Asian
  - Black or African American
  - Native Hawaiian or Other Pacific Islander
  - White or Caucasian
  - Hispanic or Latino
  - Other (please describe) \_\_\_\_\_

**The following questions are about your sports physical and your feelings about genetics testing.**

3. Are you tested for the following during your sports physical? Using the list below, check “yes,” “no,” or “don’t know.” Also, check if you are offered education about the test.

Type of Test	Yes	No	Don’t Know	Offered Education
Cholesterol				
High Blood Pressure				
Sickle Cell Trait				
Eyes				
Skin				
Respiratory				
Cardiovascular				

4. How likely would you be to support **voluntary** genetic testing during your sports physical? (circle the statement that matches how you feel about this question)

## APPENDIX G, CONTINUED

## SICKLE CELL ORIENTATION AND EDUCATION (S.C.O.R.E.) SURVEY

1	2	3	4	5
Not at all likely	Somewhat unlikely	Neither likely or unlikely	Somewhat likely	Very likely

5. How likely would you be to support **mandatory** genetic testing during your sports physical?

1	2	3	4	5
Not at all likely	Somewhat unlikely	Neither likely or unlikely	Somewhat likely	Very likely

The following questions will ask about your knowledge of sickle cell disease. Please **circle** the answer that bests reflects your knowledge or opinion.

6. Sickle cell trait is a disease. (circle one)
- True
  - False
  - Don't Know
7. People with sickle cell trait carry a gene that can be passed on to their children. (circle one)
- True
  - False
  - Don't Know
8. Having sickle cell trait can affect an athlete's health. (circle one)
- True
  - False
  - Don't Know
9. Any race or ethnic group can have a sickle cell condition or be a trait carrier. (circle one)
- True
  - False
  - Don't Know
10. A blood test is needed to determine if a person has sickle cell trait. (circle one)
- True
  - False
  - Don't Know
11. People get sickle cell disease by being born with it. (circle one)
- True
  - False
  - Don't Know

The following questions are about your perceptions of sickle cell trait. **Please circle the answer** that is closest to how you feel about the statement.

12. I am at risk of having the sickle cell trait.

1	2	3	4	5
Strongly Agree	Agree	Don't Know	Disagree	Strongly Disagree

13. It is important for an athlete to know if he/she has the sickle cell trait.

1	2	3	4	5
Strongly Agree	Agree	Don't Know	Disagree	Strongly Disagree



## APPENDIX G, CONTINUED

## SICKLE CELL ORIENTATION AND EDUCATION (S.C.O.R.E.) SURVEY

14. If I were diagnosed with sickle cell trait, my level of concern would be:
- |          |     |             |      |           |
|----------|-----|-------------|------|-----------|
| 1        | 2   | 3           | 4    | 5         |
| Very Low | Low | Unconcerned | High | Very High |

The following questions are about NCAA Guideline 3c. **Please circle** the answer that best describes your knowledge.

15. Are you aware that there is a NCAA Guideline that is specific to sickle cell trait and the athlete?
- a. Yes  
b. No
16. Are you aware of any change made to NCAA Guideline 3c: The athlete with sickle cell trait?
- a. Yes  
b. No
17. NCAA Guideline 3c recommends that all athletes be tested for sickle cell trait. An NCAA guideline that recommends **voluntary** sickle cell trait testing for athletes is:
- |           |      |         |     |          |
|-----------|------|---------|-----|----------|
| 1         | 2    | 3       | 4   | 5        |
| Very Good | Good | Neutral | Bad | Very Bad |
18. An NCAA guideline that recommends **mandatory** sickle cell trait testing for all athletes is:
- |           |      |         |     |          |
|-----------|------|---------|-----|----------|
| 1         | 2    | 3       | 4   | 5        |
| Very Good | Good | Neutral | Bad | Very Bad |
19. Genetic testing in general is:
- |           |      |         |     |          |
|-----------|------|---------|-----|----------|
| 1         | 2    | 3       | 4   | 5        |
| Very Good | Good | Neutral | Bad | Very Bad |
20. NCAA recommendation 3c might result in athletes with sickle cell trait being treated unfairly.
- |                |       |            |          |                   |
|----------------|-------|------------|----------|-------------------|
| 1              | 2     | 3          | 4        | 5                 |
| Strongly Agree | Agree | Don't Know | Disagree | Strongly Disagree |
21. If I were diagnosed with sickle cell trait, I would be given less playing time.
- |                |       |            |          |                   |
|----------------|-------|------------|----------|-------------------|
| 1              | 2     | 3          | 4        | 5                 |
| Strongly Agree | Agree | Don't Know | Disagree | Strongly Disagree |

*Thank you for taking the time to complete the survey. Your answers are valuable and will help to develop a program that will be beneficial to college athletes all over the United States. Thank you once again for your willingness to participate!*

## APPENDIX H

## FOCUS GROUP INTERVIEW GUIDE: ATHLETES

*Hello. Thank you for your willingness to meet with me today. I know that athletes are busy, so I really value your time! The purpose of this focus group is to provide you with an opportunity to openly share about your experiences as an athlete on Georgia Southern's Campus.*

*The focus group should only last about 1 hour, but it depends on how much you have to share. Participation in the focus group is purely voluntary. You can choose to pass on a question or stop participating in the focus group at any time. I will be tape recording this discussion so as not to miss any of your valuable insights. This is [insert note taker's name] he/she will be taking notes during the focus group. Everything you share with me will be kept confidential. Your name will never be attached to anything you say today and all information from the interviews will be reported collectively.*

**SOCIAL ASSESSMENT/SITUATIONAL ANALYSIS**

*First, I have a few questions about pre-participation health/medical screenings:*

1. What normally happens at a pre-participation health screening?
  - NOTE: Athletes may refer to this as a SPORTS PHYSICAL!!
2. How are you informed of the results of the screening?
3. How would you like to learn about the results of pre-participation health screenings?
4. What concerns do you have about coaches or athletic trainers seeing the results of pre-participation screenings?
  - Do you think you would be allowed less playing time if your health screening revealed a health issue and your coach knew the results of your health screening?

**PROBE:**

- a. What types of things are tested for in a pre-participation health screening?
- b. Would you be willing to participate in an education session about the results of your pre-participation screening?
- c. Do you know anyone who has had a health issue to surface as a result of pre-participation screening?
- d. Do you ever think about your health when you are at practice or at games?

## APPENDIX H, CONTINUED

## FOCUS GROUP INTERVIEW GUIDE: ATHLETES

**EDUCATIONAL AND ECOLOGICAL ASSESSMENT**

*Okay, the next questions are about your knowledge of and thoughts about health screening. The NCAA recently released a recommendation that all athletes be tested for sickle cell trait.*

5. What do you know about Sickle Cell Trait?

**PROBE:**

- a. Who can get sickle cell trait?
- b. How is sickle cell trait different from sickle cell disease?

6. How many of you knew about the new NCAA recommendation?

(The recommendation says that all athletes should be tested for sickle cell trait regardless of race/ethnicity)

**PROBE:**

- a. Why would the NCAA devote a recommendation to sickle cell?
- b. Why is sickle cell trait of concern to the athlete?

7. How do you feel about the recommendation that all athletes be tested?

**PROBE:**

- a. Why?
- b. Would you support voluntary testing?
- c. Would you support mandatory testing?

8. If you were found to have sickle cell trait during a pre-participation screening, how would you feel?

**PROBE:**

- a. How do you think your coach would react?
- b. How do you think other players would react?

9. Do you think this recommendation will have more of an effect on some players than others?

**PROBE:**

- a. If so, How?

10. Are there differences in how Caucasian and African American athletes are treated on campus?

- a. What are the differences?

11. There is fear that NCAA recommendation 3c will cause unfair treatment to African American players because sickle cell trait is more common in African Americans. This leads people to think that

## APPENDIX H, CONTINUED

## FOCUS GROUP INTERVIEW GUIDE: ATHLETES

12. African American and other minority players might be discriminated against by being allowed less playing time if found to have the sickle cell trait.
- What are your experiences with any type of racism in college athletics? (Not necessarily health related)
  - Do you feel that there would be discrimination against African American Athletes or an athlete of any race found to have sickle cell trait because of this recommendation?
13. In your opinion, what are the long term consequences of recommendation 3c? (good or bad consequences)

**INTERVENTION ALIGNMENT/ADMINISTRATIVE AND POLICY ASSESSMENT**

*Now, I would like to ask you a few questions about how you would like to be educated about your health:*

14. What is a typical day like for you?

PROBE:

- a. If you needed to attend an education session about your health, when would you be able to do it?

15. How would you like for a health education session to look?

PROBE:

- a. Would there be a DVD, Pamphlets, etc?

16. Who would you like to receive the health education from?

17. What are some ways you would improve upon the pre-participation screening process?

**ENDING QUESTIONS/CLOSURE**

18. Is there anything else you would like for me to know about anything we discussed today?

*Okay. Again, thank you for your time. I really appreciate everyone's input. You have been extremely helpful to me today. Please remember that what we talked about today is confidential. Please do not discuss the focus group with anyone who was not in attendance. Every athlete's, coaches, and athletic trainer's thoughts and opinions will be considered in this study, so they will have an opportunity to respond to these questions as well. I will also be emailing you to give you an opportunity to review the transcript of this focus group so that you can verify all that was said today. Thank you. Have a great day!!*

## APPENDIX I

## INTERVIEW GUIDE: HEMATOLOGISTS

*Hello. Thank you for your willingness to meet with me today. I know that you are busy, so I really value your time! The purpose of this interview is to gain your insights, as a medical professional, on necessary components of a SCT education program for athletes and coaches.*

*The interview should only last about 1 hour, but it depends on how much you have to share. Participation in the interview is purely voluntary. You can choose to pass on a question or stop participating in the interview at any time. I will be tape recording this discussion so as not to miss any of your valuable insights. Everything you share with me will be kept confidential. Your name will never be attached to anything you say today and all information from the interviews will be reported collectively.*

*First, as you may know, the NCAA recently recommended that all athletes be tested for sickle cell trait during their pre-participation medical exams. As you may also know, this recommendation has been met with some controversy.*

1. With your knowledge of sickle cell trait and exercise, speak as to the medical necessity of this type of recommendation.
  - a. Did the NCAA come to this decision too quickly?
  - b. How do you feel about ALL athletes being tested?
2. Do you think athletes with sickle cell trait will be treated unfairly as a result of this recommendation?
3. What are the medical implications of this recommendation as it relates to the history of sickle cell trait screening.
4. What are the social/behavioral implications of this recommendation?
5. What information should be included in an education program for coaches?
6. What information should be included in an education program for athletes?

PROBE:

- a. Who should deliver this education?

**ENDING QUESTIONS/CLOSURE**

7. Is there anything else you would like for me to know about anything we discussed today?

*Okay. Again, thank you for your time. I really appreciate your input. You have been extremely helpful to me today. I will be emailing you to give you an opportunity to review the transcript of this interview so that you can verify all that was said today. Thank you. Have a great day!!*

## APPENDIX J

## INTERVIEW GUIDE: COACHES, ATHLETIC TRAINERS

*Hello. Thank you for your willingness to meet with me today. I know that you are busy, so I really value your time! The purpose of this interview is to provide you with an opportunity to openly share about your experiences with NCAA guidelines as a coach/athletic trainer on Georgia Southern's Campus.*

*The interview should only last about 1 hour, but it depends on how much you have to share. Participation in the interview is purely voluntary. You can choose to pass on a question or stop participating in the interview at any time. I will be tape recording this discussion so as not to miss any of your valuable insights. Everything you share with me will be kept confidential. Your name will never be attached to anything you say today and all information from the interviews will be reported collectively.*

**SOCIAL ASSESSMENT/SITUATIONAL ANALYSIS**

First, I have a few questions about pre-participation health/medical screenings:

1. What normally happens at a pre-participation health screening?
2. How are the athletes informed of the results of the screening?
3. What would be the best way for athletes to learn about the results of pre-participation health screenings?
4. Would you have concerns about coaches, athletic trainers seeing the results of pre-participation screenings?

**PROBE:**

- a. What types of things are tested for in a pre-participation health screening?
- b. Would you be willing to participate in an education session about the results of your athletes' pre-participation screening?
- c. Do you know anyone who has had a health issue to surface as a result of pre-participation screening?
- d. Do you ever think about your athletes' health when you are at practice or at games?

**EPIDEMIOLOGICAL ASSESSMENT**

[INSERT QUESTIONS HERE IF NECESSARY]

**EDUCATIONAL AND ECOLOGICAL ASSESSMENT**

Okay, the next questions are about your knowledge of and thoughts about health screening. The NCAA recently released a recommendation that all athletes be tested for sickle cell trait.

5. What do you know about Sickle Cell Trait?

## APPENDIX J, CONTINUED

## INTERVIEW GUIDE-COACHES, ATHLETIC TRAINERS

## PROBE:

- a. Who can get sickle cell trait?
  - b. How is sickle cell trait different from sickle cell disease?
6. Why would the NCAA devote a recommendation to sickle cell?
- a. Why is sickle cell trait of concern to the athlete?
7. How do you feel about the recommendation that all athletes be tested?
- PROBE:
- a. Why?
  - b. Would you support voluntary testing
  - c. Would you support mandatory testing
8. If one of your athletes were found to have sickle cell trait during a pre-participation screening, how would you feel?
- PROBE:
- a. How do you think other players would react?
9. Do you think this recommendation will have more of an effect on some players than others?

**INTERVENTION ALIGNMENT/ADMINISTRATIVE AND POLICY ASSESSMENT**

Now, I would like to ask you a few questions about educating athletes about their health:

10. What is a typical day like for you?
- PROBE:
- a. If you needed to attend an education session about your athlete's health, when would you be able to do it?
11. How would you like for a health education session to look?
- PROBE:
- a. Would there be a DVD, Pamphlets, etc?
12. Who would you like to receive the health education from?
13. What are some ways you would improve upon the pre-participation screening process?
14. Does Georgia Southern have the resources to educate athletes with SCT? What are they?

**ENDING QUESTIONS/CLOSURE**

15. Is there anything else you would like for me to know about anything we discussed today?

## APPENDIX J, CONTINUED

## INTERVIEW GUIDE-COACHES, ATHLETIC TRAINERS

*Okay. Again, thank you for your time. I really appreciate your input. You have been extremely helpful to me today. Please remember that what we talked about today is confidential. Please do not discuss the interview with anyone. Every athlete's, coaches, and athletic trainer's thoughts and opinions will be considered in this study, so they will have an opportunity to respond to these questions as well. I will be emailing you to give you an opportunity to review the transcript of this interview so that you can verify all that was said today. Thank you. Have a great day!!*



## APPENDIX K

## QUALITATIVE DATA ANALYSIS CODE BOOK

CODE	EXPLANATION
<u>SOCIAL ASSESSMENT/SITUATIONAL ANALYSIS</u>	
1. DAY RIT	Daily Rituals of Athletes
2. SPT RIT	Sport Specific Rituals i.e. Sports Physicals
3. A-DES ED	Educational Practices that the athletes desire
4. C-DES ED	Educational Practices that the coaches thletes desire
5. ATH CON	Athlete's Concern About Health Information being shared
<u>EDUCATIONAL/ECOLOGICAL ASSESSMENT (KNOWLEDGE)</u>	
6. F- AD-KNO SCT	Female-Adequate Knowledge of SCT
7. M-AD-KNO SCT	Male-Adequate Knowledge of SCT
8. F-IAD-KNO SCT	Female-Inadequate Knowledge of SCT
9. M-IAD KNO SCT	Male-Inadequate Knowledge of SCT
10. C-AD-KNO SCT	Coaches Knowledge of SCT
11. C-IAD-KNO SCT	Coaches Inadequate Knowledge of SCT
12. A-KNO NCA	Athletes Knowledge of NCAA 3c
13. A-IAD KNO NCA	Athletes Inadequate knowledge of NCAA 3c
14. C-KNO NCA	Coaches Knowledge of NCAA 3c
<u>PERCEPTIONS</u>	
15. PER SCT-NEG	Athlete's Negative Perceptions of SCT
16. PER NCA	Athlete's Perception of NCAA 3c in general
17. C-PER SCT	Coaches Perception of SCT
18. C-PER NCA	Coaches Perception of NCAA 3c
19. LIAB	Athlete's perception of NCAA as a Liability Issue
20. C-RESP-SCT-A	Coaches responses to athletes with SCT as perceived by athletes
21. C-RESP-SCT-C	Coaches responses to athletes with SCT as perceived by coaches
<u>RACISM</u>	
22. PER RAC-AA	Perceived Racism by African Americans
23. PER RAC-C	Perceived Racism by Caucasians
24. INT CON	Interest Convergence- A sense that blacks are treated well because of Selfish interests of whites

## APPENDIX K, CONTINUED

## QUALITATIVE DATA ANALYSIS CODE BOOK

CODE	EXPLANATION
<u>MEDICAL EXPERTISE</u>	
25. NEC COM	Hematologists recommendations-necessary Components of a SCT
26. INT COMP	Education program Intervention Component

## APPENDIX L

## RELIABILITY OF SCALES UTILIZED TO CONSTRUCT SURVEY INSTRUMENT

*Internal Consistency Reliability Scores for Sickle Cell Disease Assessment Survey Subscales*

Subscales	Original study $\alpha$	Pilot study $\alpha$ (N=15)	Major Study $\alpha$ (N=191)
Sickle Cell Disease Genetics Knowledge subscale	Self-developed	0.44	0.55
<sup>a,b</sup> Perceived Susceptibility subscale	0.83, 0.48	0.95	0.81
<sup>c</sup> Perceived Severity subscale	0.64	0.85	0.62
<sup>d</sup> Feelings about Carrier Testing subscale	0.55	0.63	0.64
<sup>e</sup> Health Orientation Scale	0.97	0.91	0.94

*Note.* <sup>a</sup> Surh, Cappelli, et al, 1994; <sup>b</sup> O'Connor & Cappelli, 1999; <sup>c</sup> Henneman, Bramsen, Van der Ploeg, Van der Horst, & Gille, 2001; <sup>d</sup> Barlow-Stewart, Burnett, Proos, Howell et al., 2003;

<sup>e</sup> Wooldridge & Murray, 1988

*Note.* Table utilized in Stewart (2007)